



MONASH University

What a patient and doctor owe each other; the ethics of hope and trust in a fallibilist model of the doctor-patient relationship.

John Gruner

MBBS, FRACGP, DRANZCOG, Dip Acupuncture, MBioeth

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Monash Bioethics Centre

School of Philosophical, Historical and International Studies

Faculty of Arts

Monash University

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Abstract

Over the years I have felt a level of disquiet in trying to determine what my ethical duty as a doctor requires of me when patients make health decisions likely to be harmful to their health. This particularly applies when it seems to me that a patient places a high level of trust in something, or someone based in an ill-founded belief and also when the patient ought to further consider the impact of their decision on certain others. As a clinician I seek ethical arguments to reconcile how the patient and I can determine what we ought to do in cases of fundamental disagreements in health care decision making. I propose a novel approach to this problem by developing and forging links between three constructs that I argue are based on people adopting an attitude of fallibilism. The three constructs that I forge links between are (1) a contractualist conception of what the doctor and patient owe each other and grounded upon this, (2) an account of the “ideal deliberative doctor-patient relationship”, and (3) a fallibilist conception of Evidence based medicine whereby both the doctor and patient are encouraged to co-deliberate with one another. I argue that in the ideal doctor-patient relationship, appraisal of Evidence based medicine findings, where available and relevant, ought not to be rejected outright in determining what health care decisions should be made with a patient. A doctor and a patient may show respect for one another by having an attitude of fallibilism and by being mindful of the above three constructs in attempting to understand each other’s beliefs and values, and by encouraging co-deliberation with one another. I argue that a patient should not disregard their doctor outright, nor those who will foreseeably be adversely impacted by the patient making a foreseeably harmful health decision while disregarding those others. I refer to the three linked constructs to argue that the ethical use of trust and hope in health care ought to be based upon awareness of how these emotions effect not only the patient, but also others around them.

Declaration

This thesis is an original work of my research and contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Signature:

Print Name:

Date:

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I first acknowledge the many patients who have honoured me by granting me the privilege to gain insights into what they believe and care about, often challenging me to beliefs and values that I seek to understand. Additionally, I thank patients, my staff, medical colleagues and family for giving me time to work on my research and for their feedback. I am indebted to my supervisor, Professor Justin Oakley for years of diligent, wise guidance and the Monash Bioethics Centre for the opportunity to engage in research and seminar programs. I acknowledge the late Max Charlesworth who advised me in 1999 to extend my research from the issue of informed consent in alternative medicine, to consider how people with diverse health beliefs ought to engage with each other in health care. Thankyou also to the attendees at Murdoch Institute 1998 seminar I gave, for their challenges to me on the subject of hope in those with incurable genetic diseases and lastly, I acknowledge people who gave such valuable feedback at the talks I gave at the Monash seminars and A.A.B.H.L conferences in the Gold Coast, Dunedin and Melbourne.

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Chapter 1: Introduction

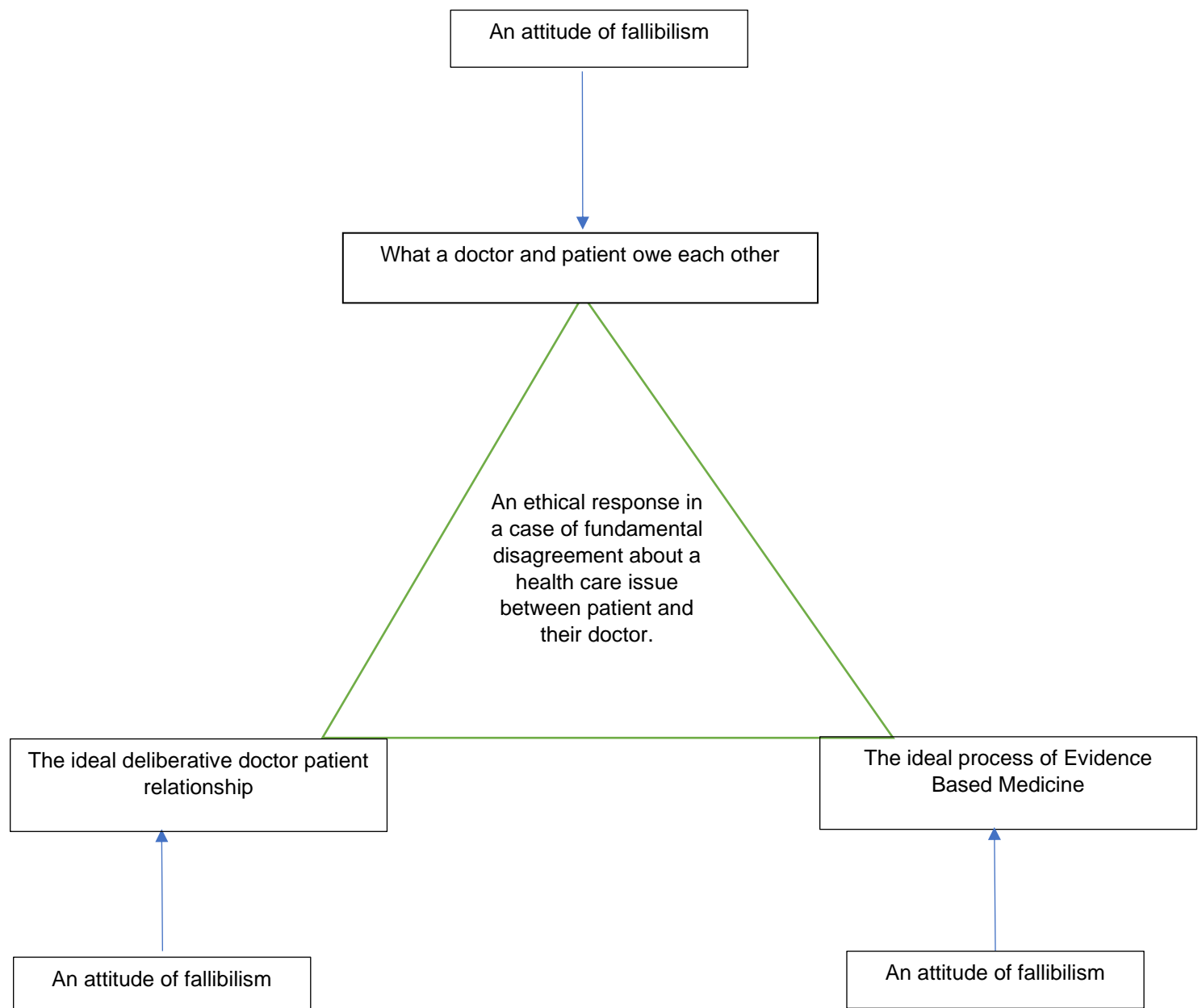
My motivation for this work was initially spurred by my months in 1986 living with Australian First Nations people who fired my interest in how medicine interfaces with different cultures, and also in the years since then, to when patients have differing health beliefs to what I have thought were reasonable beliefs. For example, every few years I have diagnosed a long-term patient with a curable cancer for which they refuse standard care measures and then seek futile alternative care, and we all eventually suffer because the patient dies prematurely. Further, for a time I practiced obstetrics and my wife became a home birth midwife; I had a much higher assessment of the risk of home birth than she had, and yet we went onto have our four children at home. As a husband, potential father and doctor I had to reflect on how I was to respond to a health care practice I that am broadly opposed to. In researching for this thesis and defending contractualist ethical reasoning, I realised that how my wife and I came to an ethical solution, was by recognising that we owed it to each other to respect and understand each other's beliefs and to find ways to decide what was tolerable to both of us in having a home birth, by deciding on principles of safety that we could agree that neither of us could reasonably reject. In clinical practice I soon found that simply attempting to give the "best available evidence" to patients who opposed childhood vaccination was not in the least persuasive (Gorman & Gorman, 2016) so I embarked on this doctoral project to find ethical reasons why those with health beliefs different to mine should engage with me in dialogue.

I will now give a brief overview of the thesis followed by a diagram that attempts to convey to the reader the overall structure of this work. In this thesis I seek to address how I as a doctor may best decide what is morally required of me and the patient

before me, in cases where the patient and I have fundamental disagreements about a matter of the patient's health care. I am seeking to find processes which both I and a patient can be guided by to determine what we both ought to do in such disagreements. Such disagreement may be instructive to us both in determining other aspects of our doctor-patient relationship. I will argue that Tom Scanlon's work on contractualism can usefully be drawn upon by a doctor¹ and a patient to determine how they ought to conduct their relationship, and what each ought to be able to expect of the other. I argue that a contractualist requirement for two people to appreciate what impact they can have on the other and to co-deliberate upon what underlying ethical theories might be more important for them is a natural fit for the doctor-patient relationship. Such a relationship in turn fits well with what we might hope for in the ideal process of "Evidence based medicine" (E.B.M.) where the doctor and the patient ought to deliberate together upon each-others' views and the views of many others. Furthermore the requirement for co-deliberation also features prominently in Emanuel and Emanuel's construal of the "Ideal deliberative doctor-patient relationship" (I.D.D.P.R.) (Emanuel & Emanuel, 1992). My thesis argues that fallibilism is the conceptual underpinning of ethical health care that may be conducted by doctors and patients who refer to the three fallibilist constructs; (1) a contractualist model of what the doctor and patient owe each other, (2) the I.D.D.P.R., and, (3) the ideal process of E.B.M. I then examine how my linking of these three constructs may be used to determine how hope and trust ought to be used in health care.

¹ Throughout this thesis usually the word doctor, health care practitioner, practitioner or carer are used interchangeably depending on the context. Though the doctor-patient relationship is my primary focus, other people involved in patient care ought to attend to the nature of each other's obligations in the relationship and the ethics of hope and trust in the clinical setting.

Diagram 1; The schema of the three linked constructs.



In my first chapter I will argue that due to an epistemological framework and “attitude of fallibilism” (Hookway, 2012)² a sceptical approach by practitioners of health care is not only more likely to lead to more effective care but to thence promulgate a more ethical framework for ethical health care for patients.

Though I will subsequently refer to Kant, Charles Peirce is more widely recognised as having done extensive work in the philosophy of fallibilism. Peirce wrote that, “people cannot attain absolute certainty concerning questions of fact” (Peirce & Buchler, 1986, p. 106). I will contrast the lack of absolute certainty of a person who adopts a fallibilist attitude in a health care matter, with the absolute certainty of a person who holds a health care related belief dogmatically or has strong faith a belief. More contemporarily, Christopher Hookway characterises one account of fallibilism as,

A defender of global fallibilism holds that, for any proposition at all, either we can see how we might be mistaken in holding this proposition, or if we were properly rational in our reflections, we would be able to recognise the possibility of error (Hookway, 2012, p. 45).

In such a manner, a fallibilist utilizes a belief that they may revise, in order to seek better founded means of achieving their goals. In adopting a fallibilist attitude, one seeks to appreciate one’s errors and to learn from them. While I do not argue that a

² Though I will discuss a use of the term “attitude” in the final chapter and compare it to the word “stance”, here I will refer to Simon Blackburn’s explanation, (that he states requires qualification) as, “An evaluative response, usually contrasted with simple belief by its more direct connection with motivation and behaviour. An attitude is a state whose essence is contentment or active discontent with some way the world is, rather than a simple cognition of the way the world is” (Blackburn, 2016, p. 37).

global fallibilism ought to apply to all aspects of the doctor³ patient relationship, I will defend the claim that a fallibilist attitude ought to be adopted by both patients and practitioners in appraising key beliefs used when making most clinical decisions. An epistemological argument will be made that health practitioners ought to adopt a fallibilist attitude due to the inherent uncertainty of clinical outcomes, (Evans.M, 2004; Groopman.J, 2007; Montgomery.K, 2006; Rubin.S.B, 2000; Sox.H.C, 1988), and moreover that health care practice that is not based on a fallibilist approach is unethical.

While it might seem uncontentious to argue that ethical health care embraces fallibilism, health practitioners in the past have acted as if they believed that their medical opinion was less fallible than it was⁴. Patients might also regard that their own beliefs about a health issue as infallible. In contrast, I will demonstrate how the process of E.B.M. was initiated by people (such as Archi Cochrane), who adopted a fallibilist attitude in how they were uncertain that what they practiced was in fact effective care. E.B.M. processes developed further to support clinical care being guided more than it had been by the patient's perspective, as people acknowledged how fallible various standard of evidence attained by scientific methodology are in helping the individual patient, without the input from the also fallible doctor and patient. I argue that though the process of E.B.M is imperfect and still developing as more problems with its implementation are uncovered, it is an ideal that can be used as a guide by those who adopt a fallibilist attitude and seek to verify with others the basis of what is done in health care. By adopting a fallibilist attitude, a health practitioner can acknowledge that that they will make errors, and that they may have an opportunity to reduce such errors

³ Throughout this thesis, the word "doctor" may be generally interchanged with the words "health practitioner", "health carer" or "practitioner".

⁴ For example, Associate Professor Green, section 2.6.

by checking with the patient and other sources about what others believe is best care for the patient. It is important in the fallibilist process of E.B.M. for doctors and patients to appreciate that the process of E.B.M. is imperfect and it is also important for them to acknowledge that there might be a plurality of ideas about health care that, up to a point, they ought to consider.

Another motivation for me developing this thesis is my need to reflect on how I ought to have acted when being treated as a “moral other” by patients whose beliefs I sought to challenge, because they had (in my opinion and by most of society’s standards) certain ill-founded and ill-informed health beliefs that they were certain were infallible. By “moral other” here, I am referring to Josh Greene’s work (Greene, 2013), whereby he claims that people can be helpfully understood as being part of certain “moral tribes” where the people involved in a “tribe” are assumed to all hold one moral view or set of values, and by the very membership of that group are held by those of another tribe to be morally wrong or suspect in their moral beliefs and values. Members of a “moral tribe” are certain that those in their tribe are “right”, and that those outside it are “wrong”, by virtue of whether they are a member of the tribe or not. An effect of such “tribalism” can be that one person or group “locks out” those who they consider to be moral others, in the sense that those of the “in tribe” will not even consider that the “moral other” is worthy of dialogue, or even recognition that the “other” person’s views matter. However, just because a moral position is being put forward from a community different to one’s own, it does not follow that this moral position has less “truth” or veracity, whatever is construed as the means of resolving moral differences. It seems plausible to hold that a member of one tribe may make ill-founded assumptions about a member of another tribe’s level of esteem or disrespect for them. This may occur because a tribe member believes that “the other” tribe considers that their tribe is

morally inferior. In the possible example of a 25-year-old patient who shuns doctors as all being of a different tribe on the side of the pharmaceutical industry that the patient despises, the patient might assume that their doctor's morality is a defective morality and that the doctor disrespects them, despite the doctor claiming to care for them. Such tribalism can foster disrespect and can render dialogue difficult.

In a further example such "moral tribes", I have met a few patients for the first time who opposed vaccination, and they would not discuss their beliefs with me saying; "You are a doctor and will not understand", or that there is no point in having a dialogue with me as "I am a doctor and a lackey of the pharmaceutical industry". These patients were not prepared to discuss their health belief with me, having decided that they would not change their health-related beliefs, and further, they held a belief in an infallibilist manner that there was no point in ever talking to a doctor about vaccines. Similarly, I have heard doctors implausibly dismiss all naturopaths or chiropractors as being a group who such doctors falsely believe "simply cannot be reasoned with"⁵ and that "there is no point in attempting to engage in dialogue with people who cannot be reasoned with" or such doctors have claimed that elements of naturopathy are unethical as they are irrational and unscientific. However, I will argue that "Reason" (see sections 3.6 and 4.2) alone is not the sole determinant of the sort of health care that doctor should engage in.

I argue that dogma that rejects any possibility for dialogue or reflection is a form of hubris which leads not only to epistemic error but importantly may lead to the disrespecting of persons to whom respect is due. It is wrong to hold a dogmatic position that all people of a group think or believe the same way on all issues and to the same

⁵ By "reasoned with", I mean to engage in a dialogue in where both parties can agree to abide by certain values, norms of logic and standard views of epistemology. See section 3.6.

degree, and I will defend the claim that such firmly held beliefs that are the basis of a dogma may lead to disrespect of “others” as ones whose beliefs or existence matters less than one’s own. The good doctor-patient relationship is ideally unquestionably based on elements such as trust and mutual respect, and I argue that strongly dogmatic positions⁶ might threaten such mutual trust and respect and can degrade the respectful dialogue that patient and doctor owe each other.

Though the first chapter concerns dogma and fallibilism I will provide a brief account on the word “respect” that I frequently refer to as a key consideration in finding justificatory reasons for how the doctor and patient ought to relate to each other. Respect at its most minimal meaning might refer to acknowledging the existence of another person or thing. Stephen Darwall refers to this as “recognition respect” (Darwall, 1977) which I will argue is at the core of what obligations are owed to each other in the ethical doctor-patient relationship. For example, we might recognise that another person warrants a degree of our respect as they are like us. With such respect might come a feeling, cognition, or attitude that the other is special, or that we might owe them something as they are (even if remotely) like us. Another kind of respect, “appraisal respect” (Darwall, 1977), involves a degree of recognition or admiration for the other person or thing’s achievements or capabilities. While doctor and patient may have a level of positive or negative appraisal of each others’ attributes, I do not specifically make claims that this form of respect should necessarily be core to the doctor-patient relationship. Both meanings of respect imply that what or who is respected has some value to the holder of respect. Such a perception of value in others (or an aspect of them) might be motivated by an appreciation of how the one who holds respect ought to think or act towards what/who is respected. In this manner

⁶ That is; dogmatically held beliefs held by the doctor *or* the patient.

respect is linked to ethical thought and determining what people owe to each other in their relationships as is discussed in the next chapter.

In chapter two I focus on how the uncertainty of the doctor and patient in matters of health care and the fallible nature of decisions that can be made with respect to the patient's health care might plausibly be thought as fertile ground for disagreement between doctor and patient about health decisions. These difficulties in health care decision making, can in turn be problematic for the patient and doctor when determining what they ethically owe to each other in cases of disagreement about a major health decision. If doctor and patient acknowledge that their health beliefs might be fallible and recognise a level of uncertainty in the outcome of their health decisions, they might also acknowledge that a plurality of health beliefs are possibly held by the other party. A patient ought to recognize that a particular health belief or decision might impact on other involved people in significant ways and at times the patient might be aware that others are concerned about their health decision.

The questions I attempt to answer in this chapter include: What health decisions or beliefs ought one or the other person tolerate or not tolerate and why? Ought a doctor or patient to attempt to dissuade the other from what they believe is an ill-founded health care decision? How much ought one person to attend to the other's view? What, if any duty has the patient to the doctor (or to others who the patient knows cares for them) should the patient choose a health direction that they know that the doctor (or known carers) is uncomfortable with? The bioethical literature is extensive on what the doctor owes the patient, for example a duty of care, beneficence, enabling informed consent where possible and so on. However, how do doctor and patient determine what the patient ethically owes to the doctor and the doctor-patient relationship in cases of disagreement over, for example, values as relevant to health? What does the

patient owe to their loved ones who will foreseeably be affected by their health care decision? For example, a patient might claim that their freedom to choose a health path (that they are aware others who care for them consider is ill-founded) is the most important value for their health care. In cases of fundamental disagreement about not just evidence but values, how do the two parties determine what is right for the other to do with respect to and for the other?

In this chapter I argue for the three associations illustrated in diagram 1, that I will further support when I apply them to the ethical use of hope and trust in health care. Patient centred care rightfully has the patient at the centre of who is cared for in the model of the I.D.D.P.R., which refers to processes of E.B.M. The patient's circumstances and preferences are central to decision making. However, the words "patient centred" could be thought to suggest that the patient is also to be understood as being at the centre of others, for example their family and others such as the doctor. However, I will highlight how patients do not generally make major health decisions in a social vacuum where no one else is impacted by them or cares for them in some way. It is hard to think of a circumstance where such a health decision cannot affect someone else in some way, and that other person may therefore need to be considered. In part, the patient owes it to the doctor to recognise that their doctor is a person, with expertise in medicine and who spends a variable (often large) amount of their life committed to honouring the duties of a doctor, including the duty to care for and act in the best interests of the patient. In the cases I will discuss where the patient makes a major health decision that they are aware is troubling to their doctor (or other carers or family), I will argue that the patient owes it to the doctor to show the doctor a level of "recognition respect" (Darwall, 1977) and to at least consider the doctor's views thereby honouring the account of the ideal co-deliberative relationship that I will

discuss in this chapter.

In the third chapter I apply the above schema that links the three constructs (see Diagram 1) and I argue that health practitioners ought to confine themselves to supporting and helping patients to develop various kinds of well-grounded “informed hope” regarding health care rather than a type of “radical hope” for miracles or for objects of hope that are impossible to attain or are based on misguided beliefs. I also argue that in matters of health care, patients are morally entitled to have access to the best available health information that their doctor can give them, to enable patients to discern what they can realistically hope for in their health. Also, patients can justifiably be offered care, including dialogue about evidence and ways to assess such evidence, by a health practitioner who nurtures an environment for “informed hope”.

In this chapter I describe differing notions of hope and differing types of hope that are derived from more or less well-grounded⁷ deliberative processes. Though a patient might hope for almost anything in health care, I defend the claim that health care ought to be more concerned with what is plausibly foreseeable rather than what is fantasy or at times dogmatically held faith. There are limits to the sorts and extent of grounds for hope that a patient may reasonably expect from health care, and to the nature of hope that a health practitioner ought to permissibly support. This is because what we hope for, particularly in health care, can have implications for others as well as ourselves. Practitioners use hope unethically when they encourage a doctor-patient relationship where the patients’ expectations of the doctor are too far reaching, or when a practitioner offers grounds for hope based on claims that the practitioner purports to be infallible. On the other hand, patients can place too great a burden on

⁷ By “well-grounded”, I mean based on reasons and evidence we can agree are good evidence for that situation or belief. At times well-grounded can also refer to what is based in reality.

practitioners if the patient hopes for things that are too poorly grounded, and the practitioners is conflicted in trying to support what a patient hopes for. In such circumstances practitioners and patients owe it to each other to not only reach shared health care decisions about what is prudent for the patient, but also to show respect for one another by considering how what they hope for might impact one another.

It is therefore important to present a definition of health care that embraces the ethical use of hope by patients and health practitioners, and a discussion of the types of hope that a health practitioner can permissibly support, in a principled manner. I argue that an accurate account of the concept of hope in health care reveals that it is not possible for a practitioner to give hope, in and of itself,⁸ but that practitioners can nevertheless demonstrate ethical patient care by professionally being motivated to pursue the patient's interests, and by aiding a patient to know more about their health condition, in addition to informing the patient of current views about effective treatment options. In these ways, a patient is enabled to develop "informed hope" which positions them better than they otherwise would be to allay despair. While indeed the idea of "giving hope" might not often be thought to involve giving an emotion or a feeling, as opposed to giving grounds for hope, I seek to highlight this difference in the use of the term "hope" in health care. The reason to highlight this difference is that while a person can give another person the grounds for hope, I argue that one person might show but cannot give their emotion to another – as they can for example, give an idea to another person. I will also argue that care that provides grounds for informed hope is more compassionate than giving grounds for ill-founded or misguided hope.

⁸ Similarly, a practitioner cannot give a patient "substantial understanding" or trust, as a patient's understanding and trust are states that are attained by the patient, rather than phenomena which are handed over by a practitioner to the patient. It is not possible to give someone a feeling, though I may provide the substrate for feelings in others.

Further I will discuss differing accounts of hope to help substantiate my claim that ethical health care supports patients developing where possible, well-grounded, informed hope over hope based in fantasy - i.e. the kind of hope that while a genuine form of hope, is a hope for something that can never plausibly foreseeably eventuate. I will later argue that in health care what is commonly called “false hope” is better termed “misguided hope”, as the hope is genuine, but is derived from poorly founded beliefs. By attending to the nature and genesis of hopes in health care and assisting patients to find well-grounded, foreseeable grounds for hope, a case may be made that one of the important aims of health care, is to avoid a patient’s self-implosion, by nourishing well-grounded, informed hope that seeks to avert despair.

In some more alternative practices such as such as faith healing or very paternalistic styles of medicine, practitioners may misrepresent the nature of hope and claim to “give” the patient hope itself (even though conceptually it is not possible for one person to give hope), and indeed might adopt a quasi-religious role. However, I will argue that such “faith healing” is largely not health care, and that it is wrong for such a practitioner to claim to be offering health care when they are operating in the religious domain, whether or not they are competent practitioners of complementary medicine or of religion. I do not contest that a patient can feel care from faith healing. However, I will argue that there are differing types of hope and that ethical care of a patient risks being undermined if patients and health carers conflate the types of hope that occur in the spiritual domain with the more reasonably foreseeable requirement for the ethical use of hope in health care.

By attending to emotional factors and their origin that lead to a health-related hope and by considering more well-founded grounds for what is hoped for, patients and doctors can retain a fallibilist co-deliberative professional relationship. A doctor owes

a patient what the patient is due from the doctor as medical expert who can offer medical advice, and assistance, and not only on in relation to the specifics of medical care. In addition, the doctor has a role in facilitating co-deliberation with the patient as to what the patient can and ought to hope for in their health care. In the fallibilist ideal deliberative patient doctor relationship, the patient ought to not reject outright a practitioner's suggestion of dialogue with the patient about what can and ought to be hoped for in many clinical settings.

The final chapter will focus on firstly the nature and then the moral implications of trust in the doctor-patient relationship. By referring to conceptual associations in diagram 1, I discuss how and what/who the doctor and patient trusts might have significant effects on not only how they treat each other, but on their lives and the lives of others who depend upon them. I apply the three associations of diagram 1 to build and argument for the ethical use of trust in health care. I will argue that though trust might be an emotion of an agent that is based upon various reasons that others may consider less or better founded, there are good grounds for holding that a person's trust (or distrust) is at least one emotion that is special in the way that it can affect others. How and what a patient trusts might affect what they believe they owe to others and what others owe to them. Particularly in some parts of health care, a patient's departure from health has the potential to place great burdens upon other people. Doctors and patients ought to pay particular attention to the types of trust that they hold in health beliefs or practitioners, due to the effects that their trust might have on certain others who have justifiably thought themselves as especially significant to the patient.

I will first discuss why it is important to consider what types of trust ought to be cultivated in the schema of the three linked constructs (represented in Diagram 1) ,

and I then go onto discuss the moral implications of some of these types of trust in the setting of the doctor-patient relationship. I will start with a quote that might illustrate why our trust might be important in the way that it can influence us.

Trust gives rise to beliefs that are highly resistant to evidence. While affective attitudes can't be wilfully adopted in the teeth of evidence, once adopted they serve as a filter for how future evidence will be interpreted (Karen Jones, 1996, p. 16).

If we accept Jones's statement then, we may begin to understand why some patients and health practitioners are resistant to attending to the opinions of each other. Trust and also distrust might have filtering effects in how we interpret evidence or attach value to such evidence. If a doctor has a high degree of distrust for the advice from a patient's naturopath, the doctor might find it hard to properly engage with the patient in a discussion as to why the patient seeks the doctor's support for aspects of the naturopathic treatment. A patient might get the impression that the doctor is not listening to them properly as the doctor distrusts the naturopath's advice and will not even consider the naturopath's advice. An impression of the doctor not listening might be seen as disrespectful by the patient. In a similar manner a doctor might feel disrespected if a patient signals to the doctor distrust in the doctor as the patient feels that doctors are overly influenced by the pharmaceutical sector as is argued occurs in publications such as "Bad Pharma" (Goldacre, 2012). The manner in how a doctor and patient come to have trust and the extent to which they feel an attitude of trust can plausibly affect how much respect is shared between the doctor and the patient. For this reason, it is important for the doctor and patient to be self-aware in how they trust as their trust may affect not only their relationship, but also their relationships with others.

I will present arguments that trust may be more or less cognitive in its basis. The manner in which come to trust that a salesperson will sell us the right cosmetic, might differ from the manner in which we come to trust (and in addition the sort of trust) in our neurosurgeon. While a person may trust something along a continuum with more or less deliberation, trust may also be based on what others appraise as more or less well-founded grounds. A patient may trust something to the extent that they are resistant to considering evidence that others, whom they ought to respect, regard as well or ill-founded evidence. However, to trust something to the degree that the patient disregards the evidence that others wish them to consider might lead the patient to not only make an imprudent health care decision but also to act wrongly towards others.

I argue that health practitioners ought to foster patient trust that is *tempered* by consideration of reasonable evidence and trust that does not reject without deliberation, what is considered to be well-founded and credible evidence by others who the patient realise cares about them. It is plausible to hold that our biases might affect what we trust and what we then will “filter” as being credible evidence. Given that what someone trusts can lead them to be resistant to what others encourage them to consider, I argue here that ethical care requires health practitioners to at least try to reflect on known prevalent biases that influence health practitioners (Blumenthal-Barby & Krieger, 2015; Saposnik, Redelmeier, Ruff, & Tobler, 2016; I. Scott, Soon, Elshaug, & Lindner, 2017) and to reflect on whether they have such biases.

A spectrum character of trust may exist with at one end of the spectrum, types of trust that have been formed with a lot of cognitive effort and co-deliberation with others. In such types of trust the trustor can adopt a fallibilist attitude and is open to appraising new evidence to ensure that what or whom they place their trust in is actually

trustworthy. I argue that such qualified trust can be seen to be encouraged by the ideal process of E.B.M. Towards the other end of the spectrum might be a form a trust more akin to dogmatically held faith, where the trustor comes to trust something or someone with little cognitive effort and rejects any need to appraise what others may seek to show them as they feel so committed to what they have faith in. Such a person may have such a strong emotion of faith in what they trust, that they feel justified in feeling that they have no need to further appraise beliefs that support or might refute a basis of their faith. This is not to say that all forms of faith lack any cognitive appraisal. However, if a patient of a practitioner trusts something with a form of trust that is like the type of dogmatically held faith that rejects any possibility that the faith can be doubted, it might be hard for such a person to see reason that they should appraise the views of others. Such an infallibilist degree of trust that blocks any further consideration of evidence by the one who trusts may disproportionately bias people to defer effective care, that they would not have normally deferred. Such trust can also lead a person to disregard outright the views of another person who seeks to have a dialogue with them.

Importantly, trust in health care ought to be qualified, in the sense of being “limited”⁹ and the health practitioner ought to be suitably qualified, in terms of their credentials and character¹⁰. Ill qualified health practitioners who might foster trust based

⁹ By limited, I mean that the trust given may occur only be in one part of a person’s life, for a limited *time*, and to a limited *extent*. That is such trust is conditional. For example, my trust in an ophthalmologist to do my cataract surgery is limited to the procedure I agree to and not plastic surgery correct my sagging eye lids. Nor do I trust the ophthalmologist to assist me in other broader medical matters, or yet broader still in matters of my finances or the assisting me in my spiritual life. Contrasted, less limited trust may be unusual, in trusting the ophthalmologist to do what- ever they want to me as pertains to my health. However still such trust is *limited* to affairs of health. Yet another example may be our trust in our spouse. Though we may trust our spouse in many far-reaching ways, still this most wide-ranging form of trusted relationship, may not extend to *all* matters, as we may not trust our spouse with certain areas of our life. (Such as choice of what frock\tie to wear out).

¹⁰ By character, I mean that we reasonably expect that a health practitioner ought to have certain virtues, such as being diligent in attending to the patient’s health care, or honest with the patient etc.

principally on feelings of good rapport between the doctor and the patient¹¹ may be what some patients “like” and may be an easy way for a patient to form (what more superficially seems to be) trust but may not serve the patients’ health interests. Following such practitioners’ advice may not be what the patient ought to follow when considering the impact of their health decision on those who are important to them, or who depend upon them to remain healthy.

I will defend arguments that, for a health practitioner to be justifiably regarded by all parties as trustworthy, a practitioner must not only be competent¹² and qualified (Karen Jones, 2012, p. 76), but also ought to feel a sense of beneficence towards the patient to honour the patient’s trust. In this manner, the patient’s trust is not only an emotion and an attitude of the patient, but that trust is duty setting to the practitioner to be trustworthy and to fulfil the ethical requirements of the health practitioner. As a spade is in part defined by its function, I am arguing here that trust is partly defined by its function as duty setting. I will argue that a health practitioner, to honour their patient’s trust and act as the patient might reasonably expect (in the setting of the schema of the three linked constructs), may be justified in attempting to dissuade a patient from pursuing a particular therapy where the patient owes it to others and themselves to consider what the process of E.B.M. has to offer. I will discuss how the circumstances around Steve Jobs deferring potential curative cancer treatments, may be a case where health practitioners were morally justified in fulfilling a duty that they owed to Jobs¹³, by attempting to dissuade him from what was plausibly considered by his

¹¹ Good rapport is not to be conflated with a “good therapeutic relationship”. Rapport may be an important constituent part of the doctor patient relationship but is not the totality of what constitutes a professional therapeutic relationship. Rapport may be “good” in the sense of being fitting many criteria for what definition of rapport we recognize; however, rapport may not be good, in the moral sense of good.

¹² For example, to practice medicine or nursing.

¹³ In the setting of the schema of the three linked constructs.

carers to be futile therapy. Jobs's wife and health practitioners were justified in attempting to encourage Jobs to be cautious in what he initially trusted, and to consider them and not allow the belief in what he firmly trusted, to lead him to be so resistant to the evidence that they presented to him. They were justified in *not just* presenting Jobs with the "best available evidence" but, by referring to the associations of diagram 1, to ask Jobs to consider that Jobs owed it to them to consider how they would be affected by what he initially trusted. I believe this to be a novel approach of this thesis, in that I claim that in some circumstances health practitioners ought to encourage patients to have dialogue about not only patient values and best available evidence, but also about what they owe to each other.

Finally, I will argue that while it may be clear that a doctor ought to be trustworthy and that the patient ought to be able trust that a doctor will honour certain patient expectations, the expectation of trust and trustworthiness ought to be two way. Such a two-way nature of trust is supported by an account of the duty setting nature of trust, whereby it is claimed that what a person's trust can impose certain burden and duties on others. A doctor ought to be able to trust that the patient will honour certain social and doctor expectations of how the patient treats the doctor, because of what the patient (or their guardian) has signalled to the doctor.

Chapter 2: Ethical health care embraces fallibilism

2.1 Introduction.

I initially set out accounts of the way we generally make judgements, not only in matters of epistemology but also in matters of morality and I then argue that fallibilism (as a form of scepticism) should be regarded as playing a fundamental role in determining what ought to occur in health care. I argue that fallibilism provides a plausible basis for a novel defence of the process of E.B.M., and I demonstrate how the humility in adopting a fallibilist attitude may more readily enable us to see our need to be self-reflective, and to pay regard to the perspective of other people and sources of evidence, rather than to rely upon our fallible appraisals alone. The fallibilist need to seek the views of others is a natural fit for the co-deliberation that ought to occur in the ideal process of E.B.M., in a model where the three pillars that I discuss ought to be accounted for. I contrast the ethical implications of fallibilism with a dogmatic approach in health care, in order to support my claim that we ought to adopt a fallibilist attitude in health care decision making.

2.2 Dogma

In this section I will argue that dogma accepts a finitude of enquiry and a unwavering belief that something is true. A dogmatic system of knowledge is viewed by its proponents as essentially complete, as dogma accepts that the truth is known. Within a dogmatic system, the only evolution of knowledge is the formulation of different doctrines based on that dogma; however, believers of that dogma may not dispute the core beliefs that go into a doctrine if the believers are to be aligned with a particular dogma. An example of this may be of the core belief of the “Holy Trinity” in Roman

Catholicism and the various doctrines that are held to proceed from this central dogma.

Dogma is often seen in domains of belief such as aspects of religion where truth of matters such as “the afterlife” cannot be verified. We are not able to debate the veracity of claims as to the nature of the afterlife, as any discourse over matters of the existence of an afterlife, will come back to faith¹⁴ as we have no direct evidence to work on. A person’s faith determines their beliefs regarding the possibility of an afterlife, and we might draw on evidence to support that faith, but we are not able to prove with empirical evidence for what we have faith in. A person who follows a dogma accepts a belief to be true and likely has faith in that belief. It is problematic that co-deliberation (see next chapter) between two dogmatists may be possible only to a superficial level as ultimately two people with differing firmly held dogma must accept their differences to avert conflict, as otherwise any debate will be circular and thus further dialogue might seem futile. Richard Rorty famously wrote a book titled “*Religion as a conversation stopper*” (Rorty, 1994). Rorty was specifically writing on how religion interfaces with contemporary U.S.A. politics. While on some levels it seems plausible that “religion may be seen as a “conversation stopper” it is also plausible that some religions embrace peaceful dialogue, whereas some religions are extreme in their belief in certain dogma and will stop conversation. Additionally, individuals within a religion may, to a degree, interpret a particular dogma in differing ways.¹⁵

In contrast with a dogmatist, a sceptic does not believe something to be false, but merely doubts that it is true. That is, unlike the dogmatist the sceptic does not have faith in particular beliefs, as the sceptic does not have the certainty or finality of decision that a dogmatist has. Applied to health, a sceptical system of health care is

¹⁴ This is further discussed in chapter 5.

¹⁵ And can fall into conflict if either party will not accept other religious compatriots interpretation of “their” dogma.

always developing and has at least some doubts that its current practices are effective let alone safe, in a way that a dogmatic system of health care has no internal process to do. A sceptical system aims for ways for its practitioners to better know what they do not know. In contrast to dogma's way of not letting a believer learn what the believer does not know. A very dogmatic system of health care may simply follow a certain health dogma or practitioner, and accept them as true, not needing to ask questions, beyond interpretation of fine points of the dogma.¹⁶

Another problem for dogma is the very high bar required by dogmatists for evidence to alter belief that the dogma is anything but the "only truth". Such evidence may arise as believers of a firmly held belief that supports the dogma that they subscribe to are challenged by new evidence. "True believers" who may not doubt their belief and might find it very hard to question the "assumed justified and assumed true" beliefs that are the epistemological underpinning of their dogma. A consequence of dogma is that if followers of the dogma depart too far from a central dogma with their interpretations, then the system evolves into something else, or an enquiring "dogmatist"¹⁷ may be rejected from the group whose membership is based on accepting the dogma. Expulsion from a dogmatic group might have negative social implications (Fenelon & Danielsen, 2016) for the dogmatist and can therefore be a motivating force for a subscriber to the dogma to discount salient evidence that challenges the dogma's tenets. A member of a group might seek to avert being disrespected (or worse) by others of the group and avoid being seen to publicly doubt the dogmatically held, infallibilist¹⁸ beliefs of the group. In such a setting, a person with firmly held dogmatic

¹⁶ Problematic in dogma-based systems is as to how liberal with interpretation an individual devotee may be before they are no longer followers of that dogma. Perhaps in reality people believe dogma to differing levels?

¹⁷ That is, a person who adheres to a dogma.

¹⁸ A person who holds an infallibilist position on a belief, might use such infallibilism to support their dogmatically held beliefs. In this manner infallibilism and dogma are linked.

faith seems likely to accept that they are in possession of uniquely justified true beliefs that underpin their dogma, and evidence that may counter their dogma is regarded by them as “impossible” or “absurd”.

For example, there has long been in the Roman Catholic Church a doctrine of “Papal infallibility”.¹⁹ While I do not here seek to demonstrate that Papal infallibility is false, the doctrine might have potential to “blinker” people from evidence that they ought to have considered²⁰. My understanding of Papal infallibility is that the dogma holds the faithful ought to accept that the Pope speaks God’s word with respect to issues of faith and morality and cannot be wrong in these domains as he is infallible. By this doctrine although the Pope can err in other matters²¹, while the Pope sits in his office as the Pope (“ex cathedra”) the pronouncements he makes with reference to the faith or issue of morality are “irreformable”²². However, Pope Francis humbly sought an apology from victims of child sex abuse on 7/7/14 and was quoted to say, “I beg your forgiveness, too, for the sins of omission on the part of Church leaders who did not respond adequately [to reports of sex abuse].”²³

What has become recognised as the widespread inaction on child sexual abuse in many parts of the Roman Catholic Church is not a matter of faith, it is a matter of morality. While it may be contentious whether this indicates that past Popes were not, after all, infallible in what is a moral matter, past church leaders, perhaps including

¹⁹ “Infallibility means more than exemption from actual error; it means exemption from the possibility of error” from “Infallibility.” By Patrick Toner. The Catholic Encyclopaedia Vol. 7. New York: Robert Appleton Company, 1910. 9 January 2019

²⁰ In Papal language this may constitute a “sin of omission”.

²¹ Bill Piatt writing on Papal infallibility said, “It does not mean the Pope cannot sin. It does not mean the Pope cannot make errors in his administration of the Roman catholic church. It does not mean the Pope cannot err during ordinary discussions of theological matters”(Piatt, 2015, p. 564).

²² The context of this word is from; “the divine Redeemer willed that his Church should be endowed in defining doctrine regarding faith or morals; and that, therefore, such definitions of the Roman Pontiff are of themselves, and not from the consent of the Church, irreformable.” From the first Vatican Council in 1870.

²³ <https://www.bbc.com/news/world-47201647>

past Popes, have in the words of the current Pope, sinned. The Roman Catholic Church's systemic failure to handle the problem of paedophilia, though not unique to that church, has clearly harmed people. Some priests were wrong in refusing to heed cries for justice and help from victims and their families. Though some (indeed many) priests were complicit in the paedophilia of the time, it is plausible to hold that some in that religion had dogmatically held beliefs²⁴, such as the belief that priests could not be paedophiles due to a priest's sacred vow of chastity. However, the medieval philosopher Michele de Montaigne argued that dogma does not allow us to know what we do not know (Guild, 2014). In following dogma, we are led to take a side and to reject the opinion of others. In such an environment of intractably held faith in dogma (as occurred in some member of the Roman Catholic Church at that time) some priests seemingly refused to believe that they themselves or their brothers could "do evil". In such an environment it is not surprising that the Roman Catholic system failed to properly deal with paedophilia in its clergy.²⁵ Dogmatic systems of emotion and deliberation have the potential to not only ignore and disrespect others, but to routinely "cover up" salient evidence of harms, in ways that fallibilist systems do not, as fallibilist systems can strive to uncover such systematic flaws and learn from errors as I will now discuss.

²⁴ That is, beliefs that are firmly held by the person in support of the dogma that they subscribe to and will not revise.

²⁵ Such a view held in a dogmatic or infallibilist manner, has been recently reported in the media. In the 2019 released recordings of Cardinal Pell's initial police interview, Pell was heard to say that the allegations against him of paedophilia were "disgraceful rubbish", "madness", "impossible" to claim such occurrence "after Sunday mass in such a Holy place." Quoted from; <https://www.theage.com.au/national/victoria/interviewed-in-rome-pell-called-police-claims-garbage-and-falsehood-20190226-p510a5.html> ²⁵ After the time of original writing, Cardinal Pell's criminal conviction has been rejected. One of Pell's defences was that there was "reasonable doubt" that the alleged criminal acts could have occurred in the time Pell was said to have been in the sacrosanctity with the alleged victims. However, it was not the sanctity of the sacrosanctity, or Pell's vow of chastity that made the alleged crimes doubtful to the law. It was the timeframes and other physical factors that rendered the alleged crimes not impossible, but open to reasonable doubt.

2.3 Scepticism

Scepticism has many forms and definitions but essentially refers to an attitude or epistemic system involving varying degrees of doubt or disbelief. The term sceptic can be used to mean a person who may not necessarily disbelieve a particular proposition P (as is a commonly understood meaning of the term e.g., global warming sceptic) but is someone who remains undecided about P and is seeking more evidence for or against the truth of P.²⁶ Bertrand Russell highlights the uncertainty of those who subscribe to modern scepticism by saying, “I was troubled by scepticism and unwillingly forced to conclude that what passes as knowledge is open to reasonable doubt” (Davis.W.H, 1972, p. 106).

Scepticism has been developed over thousands of years since Pyrrho but Pyrrhonian scepticism differs from fallibilism, as Pyrrhonian scepticism disputes that it is possible for an agent to hold a justified belief at all. A Pyrrhonian sceptic will go as far as crossing the road without regard to cars as he/she is not convinced that cars are there. Such a sceptic disputes the credibility (see section 2.5.3 on credence) of belief itself and might for example say,

“I can believe nothing, not even this” (Greco, 2008, p. 196). An “academic sceptic” holds a less strong position, claiming that it is dogmatic to be sure that we can know nothing. An academic sceptic is perpetually enquiring and suspends judgement on many matters, be that knowledge or the processes of how one gains that knowledge, for example via our senses. However, such an academic sceptic ultimately must make choices and hold beliefs to live in the real world. An agent must make choices to live as it is impractical not to; for example, choosing what to eat or drink.

²⁶ In contrast, the agnostic is someone undecided about the nature of deity and so I will not discuss this latter form of scepticism here in this thesis about health care.

Particularly in health care where decisions must be made to aid effective care, a patient and a health practitioner in many situations ought not to be “fence sitters”. However a fallibilist takes a more pragmatic approach (Davis.W.H, 1972; Greco, 2008; Hookway, 2012) and can have beliefs - and especially relevant to my thesis, hold hopes- and can trust some beliefs, while acknowledging that in time they may change their views.²⁷ To explain my understanding of the term, a fallibilist is a type of academic sceptic who is in a state of enquiry and strives to develop beliefs that are as well-founded as possible, while recognizing that a belief they have may become better-grounded. Nevertheless, a fallibilist realises that to live in the world she/he must hold beliefs, on probation. (By “on probation”, I mean a supervised period of appraisal and testing of the belief. Furthermore, beliefs are seen by a fallibilist as revisable given that they can fail to cohere with other beliefs.) This assumes a coherentist rather foundationalist epistemology to be the basis of what is recognised as “well- grounded”. Importantly, a fallibilist makes the best of what is known at this time and accepts compromise with respect to certainty over what they consider as well-founded. Fallibilism is a pragmatic form of scepticism and follows what is most plausible.

Doctors care for people but such care is not possible if doctors are paralysed by an attitude of neutrality towards different opinions (as would be a Pyhrronian sceptic) regarding how to care for someone.²⁸ If someone has chest pain, doctors help them

²⁷ Such a position reflects a coherence theory of epistemology rather than that of foundationalism. This argument is the matter of another thesis, but essentially by this epistemology, knowledge is formed by a lattice of ideas and beliefs fitting with one another and being consistent with other justified true beliefs, whereas foundationalism, as championed in its classic forms by Aristotle and Descartes, states that knowledge comes from basic beliefs that are true and immutable such as “I think therefore I am”. That is, according to Descartes, it is a fundamental to all our enquiry, to base further thoughts on the foundation that the very “fact” we are thinking, proves that we exist.

²⁸ The word care might be used in the sense of professional attendance to a patient where the practitioner “looks after” the patient or protects them. Care also might refer to a feeling of concern or interest in a matter, thing or person, that someone attaches value to.

as they may, and do not remain neutral as health practitioners ought to be motivated to care for patients and not stand by as aloof, intellectualising bystanders. It is widely accepted that health practitioners have a duty of beneficence (Beauchamp T.L, 2001). Compassionate care²⁹ requires action of some sort; even just holding a patient's hand is an act of care. To further illustrate the need to act despite uncertainty, Kant described the process of "pragmatic belief" in the medical encounter, where a decision is made with the agent being aware that such a decision is contingent on factors that may change, or that may be liable to an alternate interpretation, however that decision is the made with best intentions at the time. An account of pragmatic scepticism that allows for the possibility of uncertainty is found in Immanuel Kant's 1781 "Critique of pure reason". Kant writes:

"The physician must do something for a patient in danger but does not know the nature of his illness. He observes the symptoms and if he can find no more likely alternative, judges it to be a case of phthisis. Now even in his own estimation his belief is contingent only; another observer might perhaps come to a sounder conclusion. Such contingent belief, yet forms the ground for the actual employment of means to certain actions I entitle pragmatic belief ... Pragmatic belief always exists in some specific degree, which according to interests at stake, may be large or may be small" (Potter, 1993, pp. 647-648). Subsequently C.S. Peirce developed this idea into what became known as the "American school of pragmatism".³⁰

²⁹ For a discussion of compassion section 4.7 .

³⁰ An example of the application of work of the pragmatist C.S. Peirce health care is argued for by Katherine Montgomery (2006) in her argument that clinical reasoning follows an "abductive epistemology" attributed to Peirce (also termed "retroduction"). By this model a clinician uses their clinical acumen/patient's perspective with best available evidence to infer whether a patient's health issues fit a certain diagnostic or management path. Retrospectively from this hypothesis, evidence is sought to corroborate the hypothesis and action is advised on that basis. Abduction is thus referred to as inference to the best explanation. This form of induction is inherently fallibilist as it seeks corroboration of the theorem that is derived from somewhat nebulous "clinical acumen" or "experience". Abduction is not as definitive as a deductive form of inference where the truth of the premises guarantees the truth of the conclusion. Abduction of clinical care is sceptical in a pragmatic way in that

Similarly, an academic sceptic can be ever enquiring and doubting that their beliefs are true, however ultimately in caring for someone with chest pain, the doctor and patient refer to a certain set of (evolving) beliefs to aid the patient's chest pain, and must participate in health care rather than adopt an academic discourse in epistemology. In a setting of chest pain, the patient and ambulance paramedic adopt *for now* a particular view about what is right or medically appropriate to do. Patients and practitioners who are guided by the ideal processes of evidence-based medicine (E.B.M.) recognize that certain interventions for chest pain such as coronary artery stents might prove in the future to be less safe or effective than other treatments, but patients and doctors do not have the benefit of being 100 years hence, and so follow what is believed to be plausible now.

I will next argue that patients and doctors who are guided by E.B.M processes are not dogmatists as they are open to the notion that the “best available evidence” may change and E.B.M processes encourage new studies to develop our knowledge of how to treat or not treat chest pain. Patients and doctors who use E.B.M processes might do so in part as they believe that their current evidence is fallible, and they consider that a momentum of human creativity and searching will likely progress what we do not currently know. Practitioners and patients rightfully come to this position as there have been so many revisions of what has been thought to be best treatment for ischaemic chest pain³¹. Practitioners and patients who adopt a fallibilist attitude are not dogmatic, as they acknowledge that it is possible that current belief is ill-founded, therefore they act on such an understanding, hoping that they are doing the best for

the clinical course advised by an ethical carer is not necessarily “true”, but what the carer and patient come to as the best fit for the patient.

³¹ For example, the use of “clot dissolving” medicines led to the revision of how we treated patients with this issue from when I was a student to a hospital doctor.

the patient. Practitioners do the best for the patient at *this time* and hope that in the future a consensus of opinion will judge that their treatments were best available effective care” at that time.

As I will discuss in the next section, one of pillars of the ideal process of E.B.M. is the attempt to use the scientific method, due to the awareness of practitioners using this method of the likelihood of future paradigm shifts in health care practices. Thomas Kuhn described “paradigm shifts” (Kuhn & Hacking, 2012) in science whereby scientific beliefs develop with a certain set of understandings of the world that are for a time accepted by some, while appraised and reviewed by others until overwhelming evidence eventually overturns the current established paradigm, and a new paradigm becomes mainstream. In support of this fallibilist understanding of these ever changing systems Davis says in his book “Peirce's Epistemology” that,

“Modern science, perhaps under the influence of Hume, has come to feel that knowledge consists more in those things that cannot be disproved than those things, if any, that can” (Davis.W.H, 1972, p. 104).

Science has a pragmatic approach in the way it works with theories that currently stand up to testing, in that those who subscribe to scientific method are always mindful that the beliefs that they work with, may be dismantled as a new scientist forges her/his reputation by reducing the credence had in current beliefs. In utilizing process of E.B.M., care is recommended using the best available current evidence, while being honest with patients in advising that the current paradigm may change or might be ineffective or harmful.³²

³² Examples of the above process may be “Healthy Scepticism”; (<http://www.healthyskepticism.org/global/>) the association established by Dr Peter Mansfield who initiated the organisation to highlight false or misleading pharmaceutical marketing. Or Retraction Watch (<https://retractionwatch.com/>) that publicises retractions in major journals due to fraud or error. Various larger organisations like the Cochrane Collaboration attempt to give updated met-analyses of latest pooled evidence to assist clinicians and patients in decision making. More extensive discussion in this area of change now follows.

2.4. The link between Fallibilism and the ideal process of E.B.M.

Before I discuss accounts of the process of E.B.M and how ethical health care may be well grounded with the process of E.B.M., I will first discuss the background to this process. The people who initiated and subsequently developed the process of E.B.M. adopted what can be plausibly characterised as a fallibilist attitude, in contrast to what they saw as the less doubting attitude of their colleagues and past practitioners, who had perpetuated less well-appraised or less self-reflective care, which was at times ineffective.

2.4.1 *Fallibilism as a conceptual grounding for the process of E.B.M.*

A health practitioner and a patient who adopt a fallibilist attitudes in how they come to make decisions in health care need not embrace all (or any) of the processes of E.B.M, however I argue here that fallibilism fits well with how the processes of E.B.M. ought to be conducted, and how these processes were developed. In this section I claim that the ideal process of E.B.M. as in turn guided in part by the process of science, represents a form of scepticism that rests on an attitude of fallibilism. I say “ideal” here because such a process used to guide clinical decision-making ought to be acknowledged (by those who utilise it with a fallibilist attitude) as, though imperfect, still an ideal to aim for. In this section I will argue that the ideal process of E.B.M. represents a fallibilist process that a patient and their doctor ought to consider, based not only on its successes, but also on the many examples of learnings from failings; these are evidence of the (developing) checks and balances that support the ideal processes of E.B.M. Such a fallibilist system may promulgate an attitude in the doctor

and the patient to be self-reflective and to consider the other's views motivated by awareness they will at times err.

By adopting a fallibilist attitude, those who are guided by processes of E.B.M. may be motivated to test whether what they currently practice is based on false beliefs. In short, Popper suggested that real science is falsifiable (K. R. Popper, 2002). That is, fake science is unfalsifiable in that it may not be contested because it stands apart from the means that we have to debate and to refute a concept. In this manner, a belief that is derived from fake science appears to have similarities to a dogmatically held belief, in the way that both may be practically irrefutable. A doctor or patient who holds such a belief might not be open to considering the views of others whom they ought to respect, as they consider that their belief cannot be anything but completely well-founded. Falsifiable beliefs derived from science that are used to make health care decisions suit the process of E.B.M., as this process often requires scientists, doctors and patients to co-deliberate and to be collaborative with one another, and to critique each other's work to find errors and actively seek out patient perspectives. Examples of forums provided by those involved in the process of E.B.M. seeking feedback about ideas with others are seen at conferences and in the publishing of patients' perspectives in journals, having patients on ethics committees which regulate research, and having patients present at conferences on subjects such as what it is like to live with certain illnesses. The "peer review system" that determines what research is published, though by no means perfect (as it may be subject to influences that steer dialogue, such as commercial interests being placed ahead of advancing clinical care³³) is a part of the process of E.B.M. which, though fallible, offers a means

³³ For examples of this, see sections 2.4.4 , 2.4.5 and 5.8 .

whereby new ideas may be discussed, appraised for errors, and then more widely disseminated to clinicians and patients.

As mentioned above, a “paradigm” might represent a system of beliefs or processes that are currently held by a community of scientists (who formulate evidence that supports processes of E.B.M.), and the process of science is construed to recurrently replace one paradigm with another as new evidence is developed that refutes the previously accepted beliefs or processes of the previous paradigm. As mounting evidence appears that falsifies the previous beliefs and processes of previous paradigms, the scientific community adjusts the ways that they understand the world.

In Kuhns’ accounts of the history of science, the ideal of scientific endeavour seems to be a very fallibilist process in the way that often scientists make their careers from developing new paradigms or falsify previous scientific evidence and beliefs. Though indeed much research simply supports or refutes past studies and is not “ground-breaking”, the overall ideal of science and the process of E.B.M seems to have brought great changes to how we see and live in our world. Certainly, in my limited 30 years of clinical practice I have seen small paradigm shifts in some aspects of my clinical practice, for example how we use medications called beta-blockers to treat heart failure and in the use of antibiotics. When I commenced clinical practice in the 1980s, the use of antibiotics and B blockers in the way we prescribed them as doctors seemed to have sound “mechanistic reasoning”³⁴ (Howick, Glasziou, & Aronson, 2010) and “had always been done” so I accepted such orthodoxies. Now with many more examples of “medical reversal” (Prasad & Cifu, 2011) (whereby clinicians reverse what

³⁴ By “mechanistic reasoning” I mean reasoning based upon a justificatory narrative of a series of scientific principles and evidence that seem to be coherent. In the past it seemed to be a coherent view that the use of B blockers was harmful for heart failure as B blockers slow the heart rate, at times profoundly.

was believed to be previous best practice and adopt another practice) in what guides my practice, or my “gut feeling” about a clinical issue being though often reliable but not rarely ill-founded, I have come to be very reserved in how I trust what is said to be “common sense” or “best practice” and attempt to keep a fallibilist attitude.

2.4.2 Those who are guided by a fallibilist attitude in health care decision making ought to be open to appraising the external evidence that processes of E.B.M. facilitates.

Ethical health care ought not to be, in principle, based exclusively on purely phenomenological factors but also ought not to be based exclusively on traditions, or some more alternative practices such as faith healing. Such practices may foster (1) unethical power imbalances (R. Macklin, 1999; Nussbaum, 1999), and (2) harmful or ineffective care where there are effective therapies. For example, for decades women were traditionally subjected to enemas before giving birth due to a traditionally held mechanistic view, that such practice averted infection, but on scientifically examining the evidence, enemas were found to be ineffective (Reveiz, Gaitan, & Cuervo, 2007) and women were spared this procedure.³⁵ Traditions and theories that “something should work” may seem to be “common sense”, however often scientific appraisal falsifies what was thought “obviously” credible.

Being inspired to bring about change to doctors doing “as it was always done” and not seeing “Reason” (see section 3.6 and 4.2) to doubt what was medically “accepted” were factors that motivated those who initiated processes of evidence- based

³⁵ That is, it *seemed to make sense* that cleaning the perineal area before birth and indeed subjecting the women to an enema, would “make the area more clean and avert infection”, but subsequent research showed such preparation of women was ineffective at stopping infections.

medicine. Archie Cochrane has been widely cited as one of the inspirations for people such as Iain Chalmers and Gordon Guyatt who were prominent in the initial process of E.B.M. Cochrane was particularly motivated to learn what treatments are actually “effective and efficient” in treating the conditions that they were supposed to treat. For example, what is said to be a cure might be no cure at all as a health condition can resolve despite or instead of treatment. Archie Cochrane discussed the possibility of, “the relative unimportance of therapy in comparison to the recuperative power of the human body” (Cochrane & Trust, 1972, p. 5) arguing that clinicians need to not assume that they practice effective care and ought to be diligent in attempting to know more about causal relationships between health care interventions and their effects on the illness that doctors treat. The Cochrane collaboration³⁶ logo depicts a meta-analysis³⁷ that showed the efficacy of a steroid used to mature foetal lungs before premature birth. The evidence of the efficacy of this intervention was available for twenty years but was not applied by clinicians in part; (it would seem now) due to doctors lack of diligence with keeping “up to date”, or because doctors were not be prepared to change their traditional practices and in part because each individual clinician did not have enough cases to realise the effects of pooled trials (Howick, 2015, p. 162). Such knowledge becomes available via mechanisms encouraged by processes of E.B.M. whereby clinicians who adopt a fallibilist attitude may gain far broader evidence from experience and sources far wider than their own clinical experience and acumen³⁸.

³⁶ The Cochrane collaboration is an organisation that facilitates and disseminates scientific research that may be used in decision-making health care decisions.

³⁷ A meta-analysis is a statistical analysis where by authors attempt to find all or many relevant research papers for an area of science and allow for the quality of the studies to provide readers with a summary of what evidence is available.

³⁸ Though it is not the objective of this these to give a full account and defence of this subject, “Clinical acumen” relates to a practitioner’s skill in making good decisions in a particular clinical setting. It involves the praxis and phronesis of medicine. Clinicians I have met often believe that increased acumen takes year to evolve, and that clinical acumen might become more “intuitive” with years of clinical practice.

Numerous studies cited by Jeremy Howick (Howick, 2015, pp. 158-187) have shown how ineffective as evidence, clinical judgement alone, can be as compared to evidence from other sources such as well conducted observational or randomised controlled trial (R.C.T.)³⁹ studies. Assisted by a fallibilist attitude we may accept that no tool is perfect and that clinical acumen is a tool based on the limits of clinical experience (Haynes, Devereaux, & Guyatt, 2002). Clinical judgement is not unimportant in the ideal process of E.B.M., but it is not dominant as the centre of control (as in older paternalist health care models). The clinician is vitally important in guiding, advising and assimilating information (Emanuel & Emanuel, 1992), where agreement has been made as to principles (neither party can reasonably reject⁴⁰), which guide us in weighing up what evidence is more salient in a clinical situation. Such evidence is additional and external to the clinician, such as observational and R.C.T.s and patient feelings/circumstances. Kathryn Montgomery Hunter has argued that the role of the clinician in the clinical decision making is in skilfully using their phronesis (or practical wisdom) that is derived from external evidence of science and clinical experience.

Phronesis.... is a means of operating in the world, a matter of understanding how best to act in particular circumstances that are not (and cannot be) thoroughly expressed in general rules. Scientific reason has as its goals precision and replicability, while practical reason enables the reasoner to distinguish better from

³⁹ I will provide an account of the R.C.T directly from a well-known medical journal. "The randomised control trial (R.C.T) is a trial in which subjects are randomly assigned to one of two groups: one (the experimental group) receiving the intervention that is being tested, and the other (the comparison group or control) receiving an alternative (conventional) treatment ... The two groups are then followed up to see if there are any differences between them in outcome. The results and subsequent analysis of the trial are used to assess the effectiveness of the intervention, which is the extent to which a treatment, procedure, or service does patients more good than harm."(Kendall, 2003, p. 164).

⁴⁰ I will discuss what these words refer to in chapter 2.

worse in a given situation (Hunter, 1996, p. 304).

Using their phronesis, as an instrument, doctors do not merely impartially divulge protocols and evidence in the manner of an impartial vessel of knowledge by an “informative model”(Emanuel & Emanuel, 1992), but use (e.g.) guidelines, or journals etc. to empirically inform their clinical experience to advise a patient how to achieve the patient’s version of good or better health, and to have a dialogue over what is “health”.

A health practitioner’s clinical experience alone might not be powerful enough to aid the doctor to pick up evidence pooled internationally from meta-analysis. Both the doctor and the patient might be unaware of variables or “confounders”⁴¹ that are causally important in matters of health care. Though not always relevant or possible to attain for many health conditions or patient circumstances, the evidence that might be available that is derived from well-constructed R.C.T and meta - analyses can assist the doctor and patient to realise that various factors are more important than they had in the past believed. A doctor’s clinical acumen may be invaluable for the individual patient, in interpreting information most relevant to the individual patient and in seeing unusual patterns, or in coming to serendipitous ideas that may be further explored, developed, tested and debated, however the evidence shows that a doctor’s clinical acumen is fallible (Howick, 2015).

I am not arguing here that scientific evidence is always unreservedly more

⁴¹ “Confounders of evidence” are given a detailed discussion by Jeremy Howick’s as scientific systems are developed in an attempt to elucidate what are “confounders”, precisely due to science’s underlying goal to elucidate and better understand bias in how we come to understandings of cause and effect relationships. “A confounding factor is one that 1 potentially affects the outcome; 2 is unequally distributed between experimental and control groups; and 3 is unrelated to the experimental intervention Failure to mask participants and caregivers can lead to several confounders, including “belief” effects, “observer bias,” etc.(Howick, 2015, pp. 66-67) .

trustworthy than non-scientific evidence or should always be used in every clinical situation. Rather I am arguing that non-scientific ways⁴² of coming to understandings in many aspects of health care ought to be used with the same fallibilist attitude as how scientific evidence ought to be considered. Where such evidence is available, appraisal of what science has to offer ought not to be rejected outright as patients and doctors otherwise might regret making decisions where retrospectively they feel they have let themselves and others down for not considering what was important evidence. This is not to say that we must always use science in ethical health care. Some authors have written that proponents of the process of E.B.M. have shown disregard for the patients perspectives and attempted to argue that homeopathy is unethical as it is poorly founded on scientific evidence (Levy, Gadd, Kerridge, & Komesaroff, 2015). Specifically, my position is in not a position that non-scientific based care is always unethical. It is antithetical to ethical care to dogmatically distrust science and the ideal process of E.B.M. to the extent that scientific evidence is deliberately and conscientiously ignored (where such evidence is available) in reaching a health care decision. I now argue that the process of fallibilist, science based E.B.M. attempts to respectfully promulgate a patient's ability to reach substantial understanding, offers excellent checks and balances, and importantly aims to encourage dialogue between the doctor and the patient by encouraging consideration of each other's standpoints and the views of many others.

2.4.3 Accounts of the process ideal process of E.B.M.

Accounts of the ideal processes of E.B.M. in health care decision-making are an interplay of (1) patient, circumstance, feelings, values and expertise, and (2) carer's

⁴² For example, my "clinical opinion" that I justify to the patient as what I call "my gut feeling", or a patient stating that they "just like" a particular treatment or practitioner.

expert acumen; and the two parties interpreting and being informed by, (3) “best available external evidence”. These “three pillars” are required as those who practice ethical health care ought to acknowledge that each pillar is fallible and needs the support of the other, depending on the unique circumstances of the health decision.

In the ideal process of E.B.M. where no one pillar is discounted outright, a strength of the ideal process of E.B.M. is the way in which it allows for mutual respect and dialogue between its participants in order to appraise beliefs that are acknowledged (by those who adopt a fallibilist attitude) might be ill-founded.

I provide three evolutions of accounts of the processes of E.B.M. here to show how the process has developed in response to feedback and further co-deliberation between its proponents. An early account that seems to have its origins in Archie Cochrane’s concerns about doctors simply assuming that they practiced effective care was,

“[the process of E.B.M. is] ...the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research.” (D. L. Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996, p. 71)

Later, the role of “individual patient” was further highlighted as “patient values” were added into this account in line with a move towards what might be termed a “patient centred approach”⁴³. Principles of informed consent were developed and are believed

⁴³ As opposed to a perhaps a more doctor centred model of the doctor patient relationship or perhaps a model that is dominantly based on doctors and patient simply, somehow, following what “the evidence” is claimed points towards.

to be an important part of the shared decision making process that ought to occur in patient care (Beauchamp, 2011). I have already mentioned that decisions that are made by using the processes of E.B.M. ought to be based on a triad of clinical acumen, best available evidence and patient values as supported by the quote that claims that,

[processes of E.B.M. require] integrating critical appraisal... of the best evidence ... with our clinical expertise and with our patient's unique biology, values, and circumstances.. (Swanson, Schmitz, & Chung, 2010, p. 287).

Or more recently another author says that,

E.B.M. requires clinical expertise for producing and interpreting evidence, performing clinical skills, and integrating the best research evidence with patient values and circumstances (Howick, 2015, p. 188).

This last account seems to build on the previous ones and suggests to me that the ideal of the “E.B.M” process, though it involves a complex interplay of actions by the health practitioner, necessarily involves an important relational aspect with the patient in order for it to be ascertained how what scientific method has to offer relates to a unique individual patient. However, such an account of an ideal of a process that I claim a doctor and patient ought to consider may be argued by some to be problematic on a number of accounts.

2.4.4 Potential problems with the ideal process of E.B.M.

A (slippery slope) argument might be made that the need for such refining of definitions for such a new paradigm of health care lends support to the claim that processes of E.B.M. are fundamentally flawed, as the accounts of the process of E.B.M. require so much re-definition that it is no longer what it set out to be. Due to such reformulations

of what the ideal processes of E.B.M. are supposed to be, “criticism has been assimilated through corrections to the original formulation of E.B.M.” (Kerridge, 2010, p. 367).

However, as Kerridge points out, it may be viewed as a strength in the way there is a dynamism in how the processes of E.B.M. change as attempts are made by those who seek to achieve the goals of ethical effective care. Kerridge represents arguments that such a “watering down” of the initial simpler definitions of the processes of E.B.M. (that seemed more readily interpretable) leads to less legitimacy for these processes. It may seem that the E.B.M. process is a weak paradigm when it keeps changing as evidence such as anecdotes are accepted in some situations that were considered low level or in- admissible as evidence in past definitions of the process of E.B.M. However, the process of E.B.M. has not been “watered down” to the degree that it has no longer recognizable for what it set out to be. The process still attempts to bring scientific methodology to (where possible and appropriate) remain a part of the shared clinical decision making process rather than being disregard outright ahead of, for example, simply the doctor’s clinical acumen or what the patient “likes”⁴⁴. Just as accounts of other processes developed over many years, so to one would expect formulations of the process of E.B.M. to develop for a system of appraising evidence in health care that was only formulated so recently. As it is hard to formulate an account how people ought to act and make decisions in the process of, for example, “world trade” or “informed consent” in all settings, it is hard to define develop a practical account of how carer and patient ought to sort out what a patient’s values and beliefs ought to be in each clinical situation. I am not aware that those who refer to processes of E.B.M.

⁴⁴ For a discussion of “likes”, see section 5.9 .

claim that it is a perfect process. To the contrary I claim that the process of E.B.M. embraces changes as it is developed by those who have fallibilist attitude who may accept that their decision-making processes are imperfect. With such an attitude, its proponents can (and should) acknowledge that the E.B.M. process is imperfect and will have ongoing failings. By adopting a fallibilist attitude those who are guided by processes of E.B.M. may almost feel justified in acknowledging that the current paradigms of E.B.M. will probably be modified or radically changed. Such people might reasonably expect that the processes of E.B.M. will develop and that with dialogue with others that they may assist in rendering the process of E.B.M. more powerful in how it might help patients. I will shortly argue that humility can be powerful, as with it comes potential for valuable self-appraisal and appreciation of the views of others. The fallibilist attitude of those who seek to improve the processes of E.B.M. can be seen as a brake on any slide into the processes of E.B.M. facing a “crisis”(Greenhalgh, Howick, & Maskrey, 2014) as (I will attempt to demonstrate that) the E.B.M process was set up to assist doctors and health practitioners to not make ill-founded clinical decisions based on just one person’s view, or a dogma or a tradition. Rather I claim that the entire process E.B.M. is set up to accommodate change as ill-founded beliefs come to light by those who have adopted a fallibilist attitude and doubted current orthodoxies. However, before I discuss examples illustrative of how the process of E.B.M. is supported by fallibilism, I will discuss a potentially more fundamental issue.

An important critique of the process of E.B.M. is that it is difficult to envisage as to how a doctor and patient may integrate the triad of, best available evidence, carer’s clinical acumen and the unique patients’ feelings, preferences, and their situation. The ideal process of E.B.M. might be claimed to be so much of an “ideal” that it cannot really be applied by a patient or doctor when trying to determine, for example, what

health care value or belief ought to be referred to in their circumstances. To quote from Tonelli who refers to David Sackett, a founder of E.B.M.,

little was said about how to actually go about integrating evidence with clinical experience, other than that it should be performed in a 'conscientious, explicit and judicious' fashion. (Tonelli, 2006, p. 249)

Data may well be valid for large numbers of patients and there may be a very low "number needed to treat"⁴⁵ for a particular condition, however it is not guaranteed that an intervention will work now, for an individual patient, as their situation may differ from trial patients. There may be no known way of predicting who the intervention will or won't work for. Evidence may be considered strong, but like knowledge, may be applied well or poorly. Accounts of the processes of E.B.M. are not clear as to which pillar of the triad ought to predominate in each unique clinical situation to reach the most ethical health care decision and its evolving definition reflects these tensions.

In answer to the critique that it is not clear how clinicians and patients ought to integrate evidence in real world consultations, we need not be prescriptive as to what proportion the components of the process of E.B.M.'s triad pillars of; best available evidence, clinical acumen or patient feelings, ought to be used in each setting as clinical encounters are so varied. That is, the views of the patient, the doctor and external evidence all ideally ought to be respected (by the doctor and the patient) in the sense of being attended to in trying to make a practical health care decision.

In each clinical setting, the patient and doctor may more or less consider each of the pillars however if they are to accept a fallibilist attitude that ought to attend to each

⁴⁵ The "number needed to treat" refers to the numbers needed that require some intervention, for that intervention to be considered successful in assisting a specified outcome.

other in determining which pillar might be more important. This is because, as claimed above, with a fallibilist attitude one can never be absolutely certain that what we believe in is well-founded and therefore may have more reason to check with others with whom we may have a dialogue. In this manner I find that the process of E.B.M. is relevant to determining what doctor and patient owe each other and is not necessarily always prescriptive in, for example always being guided by what might be thought is “best evidence”. E.B.M. processes, like the guidelines that are referred to by practitioners are not normative rules that directly guide the doctor and the patient, but E.B.M. processes may be ideally used as just one reference to guide what best care may be. By the doctor and the patient coming to an agreement as to what evidence ought to be considered for the basis of debate, there is scope for co-deliberation and attempting to account for what the effects of a health care decision might be on others. In many respects I agree with most of Ian Kerridge’s comments that health care is “complex, messy, difficult and constantly requires normative judgement” (Kerridge, 2010, p. 371), but I disagree the claim that the processes of E.B.M. systems promised “certainty, simplicity and better decision making”(Kerridge, 2010, p. 371). Further, I am not sure that Kerridge suggests that the processes of E.B.M., nor its originators, ever specifically were established to achieve such a far-reaching claim, but such a claim would in any case be an example of hubris. Sackett and Cochrane attempted to bring a form of scepticism (rather than certainty) to clinical practice that they viewed had been based on tradition or dogma and though they suggested a ranking of evidence that may be interpreted for each situation, processes of E.B.M. do not offer certainty or simplicity of decision making.

While it may be difficult for a doctor and patient to practically determine which pillar ought to bear more weight in their clinical circumstance, the difficulty of utilising the

ideal of the E.B.M. process does not necessarily support a claim that this process ought not to be aspired to and tried in the doctor-patient relationship, or that any other process ought to be used instead. It might be much simpler if a patient were to simply believe that the doctor or their medicine was infallible. However, I have argued that dogmatic ways of approaching health care ought not to apply to the doctor-patient relationship, on a number of grounds.

Though it may be difficult for a doctor and patient to practically determine which pillar ought to apply to their clinical circumstance, the difficulty of utilising the ideal of the E.B.M. process does not necessarily support a possible claim that this process ought not to be aspired to and tried in the doctor-patient relationship, or that any other process ought to be used instead. It might be a lot simpler if a patient were to simply believe that the doctor and that the doctor or their medicine was infallible. However, I have argued that dogmatic ways of approaching health care ought not to apply to the doctor-patient relationship on a number of accounts.

Some might claim that the process of E.B.M. is itself dogmatic in how it ranks evidence of R.C.T. as being the “gold standard” of evidence that ought to always apply. Indeed, some have argued that the process of evidence-based medicine appears to undermine the value of clinical expertise of a doctor, or to belittle the patient’s perspective in favour of clinical practice guidelines authored by so called “experts”. For example, elements of such opinions may be found in the following quote:

“To equate “quality” in clinical care with strict adherence to guidelines or protocols, however robust these rules may be, is to overlook the evidence on the more sophisticated process of advanced expertise.” (Greenhalgh et al., 2014, p. 3)

Hierarchies of E.B.M. based evidence are published (Guyatt et al., 2008) with rigorous meta-analysis and the well-constructed R.C.T. being generally thought of higher value than, for example anecdotal evidence, however such standards need not always apply to the ideal process of E.B.M. However, to quote Jeremy Howick,

“Even the best systematic review of randomized trials will not always guide us to the right course of action for an individual” (Howick, 2015, p. 120). For example, the harms of cigarette smoking were demonstrated by rigorous observational studies, not R.C.T. However, to suggest that those who refer to the processes of E.B.M. *always* set the R.C.T.⁴⁶ as the pinnacle form of evidence is a “straw man argument”. R.C.Ts may indeed be the best form of evidence in much health care, however R.C.Ts are not the best form of evidence in all of health care, as they have no relevance to a condition or to a unique patient and R.C.Ts may be flawed (Frank 2021, pp. 16-18). Indeed, health practitioners are encouraged to scrutinise the study designs of research papers (Slawson, 1997) to facilitate their use of research in order to draw conclusions about a matter of evidence. Centres of E.B.M. practice recognise that there are many poorly designed research projects that also might not be applicable to many patients ⁴⁷.

As evidenced by the types of studies published in E.B.M. journals and the basis of guidelines, those who utilise the processes of E.B.M. recognise that while at sometimes observational studies may have more power to demonstrate causative associations (for example in the post marketing surveillance system that is widely used scrutinize the safety and efficacy of new drugs and vaccines), at other times meta-analysis, or in certain situations, even anecdotes or just the effects of care are more

⁴⁶ The process of scientific study design supposed to optimise the exclusion of “confounders”

⁴⁷ For example, The Centre for Evidence-Based Medicine. Critical appraisal tools. Oxford, UK: CEBM; 2014 at <https://www.cebm.ox.ac.uk/resources/ebm-tools/critical-appraisal-tools> .

powerful sources of evidence for causative associations. Such care effects may rightfully be considered important by practitioners who are guided by the processes of E.B.M. In some clinical contexts there seems no need to attempt to find confounders or allow for placebo⁴⁸ effects and have need to seek evidence from a R.C.T., as the patient's feelings of care ought to be the pillar that health care is based upon. As Jeremy Howick says,

many ailments do not seem to be influenced by placebo..... For example, empathetic and lengthy consultations may not have a huge effect on acute appendicitis or meningitis. Yet even when ailments are unlikely to be placebo responsive, a sympathetic clinician could affect more general – and, arguably, equally important outcomes such as making a patient feel good” (Howick, 2015, p. 180).

In many situations the processes of E.B.M. lack adequate data from R.C.T.s and “observational studies” (John S Garrow, 2007; Gray, 2017) and furthermore a complex health condition may not be well defined, nor its natural history well understood. For example, it may be hard to scientifically research certain conditions such as fibromyalgia. Care effects may be rightfully considered to be important by practitioners who are guided by the processes of E.B.M.

In palliative care that is supported by processes of E.B.M, efficacy may not be measured by cure, but there may be other relevant measures such as pain control or less quantifiable measures such as feelings of care or promulgating dignity. Dignity

⁴⁸ I will not provide a discussion of placebo here other than to use a standard definition that, “A placebo is any therapy (or that component of any therapy) that is intentionally or knowingly used for its nonspecific, psychological, or psychophysiological, therapeutic effect, or that is used for a presumed specific therapeutic effect on a patient, symptom, or illness, but is without specific activity for the condition being treated. (Shapiro, 1997, p. 41) .

may not be subject to strict empirical analysis in the same way that “numbers need to treat”⁴⁹ to avert a heart attack may be for an intervention with Statins, but this does not mean that those who are guided by or who develop the processes of E.B.M. has no interest in promulgating health care that fosters dignity for the dying.

E.B.M. proponents accept that clinical experience and acumen are all pillars of health care decision making, but are not the sole determinant where, in addition to the patient’s perspective, there is often available alternative quality evidence, external to a clinician’s fallible opinion. Howick makes the claim that,

E.B.M. proponents have insisted on the importance of expertise as a tool when used alongside research evidence, but rarely allow expert judgment as an admissible type of evidence. (Howick, 2015, p. 160)

By adopting a fallibilist attitude practitioners who are guided by the processes of E.B.M. ought to be flexible enough to refer to any of any of its three pillars, in order to pragmatically find the best solution with the evidence available at the time. Though the instigators of the process of E.B.M. were motivated to find ways to bring more scientific methodology to the practice of medicine they did not discount compassionate care⁵⁰ that accounts for the patient’s feelings as being important in the doctor-patient relationship. For example Archie Cochrane,⁵¹ tells a story (Howick, 2015, p. 181) of once being a doctor in a W.W.2 prisoner of war camp for a Soviet soldier who was on his ward screaming while dying of pleurisy. Cochrane despaired that he had no analgesia to help the man nor means to communicate with the Soviet as no-one spoke

⁴⁹ That is, the number of people who need to be treated with what is being researched in order to avert or potentiate a certain outcome.

⁵⁰ Discussed in section 4.6.

⁵¹ Cochrane’s work was foundational for those who develop the processes of evidence-based medicine.

Russian. Eventually Cochrane provided effective care by hugging the moribund man who finally died comforted in his arms. Cochrane regrets making the initial mistake of just assuming that the man was screaming, not so much for the pain, but loneliness for being far from home amongst strangers who could not understand him. Morphine was not the sole solution but showing care and respect by the embrace was “effective care”. At times there is not “hard data”,⁵² and an E.B.M. clinician uses phronesis⁵³ to help gauge what may be effective care. Cochrane was practising an ideal process of E.B.M. by not just dogmatically following standard analgesic practices of that time but he was self-reflective in not just “directly treating the pain” and he was responsive to the needs of his patient, within the limitations of what he had to provide care with, to gauge what may provide best effective available care.

While it may be difficult for a patient and doctor to be guided by the process of E.B.M. as it is not always clear what type of evidence they ought to consider as being more important to their clinical situation, such a “messy” system is actually a strength rather than a weakness. Recognizing that the system and people who develop and are guided by the E.B.M. process are fallible is not necessarily a sign of weakness. Through E.B.M. processes facilitating those who refer to them to appraise evidence that might otherwise have not been available to them, the patient can be empowered not only to receive what is internationally believed to be currently the most effective care but also to participate in shared decision making with their practitioner.

⁵² For example, data derived from direct empirical observation.

⁵³ As is discussed in section 2.4.2

2.4.5 A fallibilist attitude enables people to improve the processes of E.B.M. by actively looking for mistakes and failings in health care.

I will now turn to examples that illustrate that through the failings of earlier processes of E.B.M. or where these processes were poorly or unscrupulously applied, those who adopt a fallibilist attitude and seek to promulgate the processes of E.B.M. have shifted paradigms of the process of E.B.M. and continue to seek to improve it. It may be argued that the E.B.M. pillar of the doctor's clinical acumen and experience may be as fallible (Howick, 2015) as the poorly constructed R.C.Ts and meta-analysis that have been retracted in journals⁵⁴. With the plethora of ever changing evidence and guidelines that many clinicians or patients cannot properly evaluate, keep up with (Davidoff, Haynes, Sackett, & Smith, 1995) or ignore as not relevant to their circumstances (Abdelhamid, Howe, Stokes, Qureshi, & Steel, 2014) it is unclear how or why a patient or doctor ought to engage in such a fallible process of E.B.M. when the "best available evidence" or "clinical acumen" might be so flawed. However precisely as doctors who adopt a fallibilist attitude ought to be aware that their acumen might be poor or their experience limited or biased, doctors who are guided by the ideal processes of E.B.M. should also recognise that they ought to seek evidence external to their own opinion and attempt to become aware of bias and account for it. In such a setting, so too the patient who adopts a fallibilist attitude ought to be open to appraising evidence that does not fit with their experiences and co-deliberate with

⁵⁴ Retractions are discussed over the next three pages.

others.

This discussion of the processes of E.B.M. has highlighted many failures and inadequacies that may be construed as both weaknesses and strengths. In short, though I will now present a list of failings that have arguably come from aspects of the processes of E.B.M, the fact that these failings have come to light may be demonstrative of the checks and balances that occur in the processes of E.B.M, which might not have occurred without a fallibilist attitude being held by those who seek guidance from the ideal processes of E.B.M. While those who claim or try to be guided by processes of E.B.M. have certainly failed or been slow to acknowledge evidence that undermines the safety and efficacy of their past practices, there are multiple cases of revisions and retractions of what is considered to be higher quality evidence. Possibly in part due to sheer size of people engaged in the process of evidence-based medicine, unethical behaviour has occurred under the guise of E.B.M., however such unethical behaviour (that I mention examples of over the next few pages) need not always to have been representative of E.B.M. overall. Many cases of failings in health care have occurred because of the poor use of processes of E.B.M., and these can be seen as examples of how the fallibilist attitude of those who try to use scientific methodology to improve the process of E.B.M have been able to uncover cases of examples of fraudulent or poorly conducted science or simply mistakes.

As a doctor who tries to maintain a fallibilist attitude and who also endeavours to be guided by processes of E.B.M., I provisionally trust certain sources of evidence such as journals or opinion leaders, while aware such evidence may be tainted by bias ⁵⁵ but also aware that the process of E.B.M. is in in turn steered by the process of science

⁵⁵ As discussed in section 5.8

with its paradigm shifts and that self-checking processes are recurrently being developed internationally. For example, it became apparent that journals published research that was more likely to gain readership of that journal and enhance the journals prestige. Such a process became known as possible publication bias (Begg & Berlin, 1989). It became clear that there is a need for trials which showed failure of therapeutic effect or adverse effects, to be brought into the public domain so that meta-analysis (where research data is appraised and pooled from multiple sources) were less weighted away from negative results (Rosenthal, 1979). Now many major journals seek out retractions (Godlee F, 2011) and publish “negative data”, where therapy was not effective, as a way for clinicians to consider what might not be effective rather than concentrating more so on the latest so called “break-throughs” which might lead more readers to that journal. Journal editors and reviewers are aware of research fraud (George & Buyse, 2015; Turin, 2014) and now ought to attempt to find ways to stop such fraud (Shuchman, 2017).

Medicine has famous past harms such as Thalidomide, the Halstead mastectomy, “deep sleep therapy”⁵⁶, and the recurrent withdrawal of drugs in phase 4 or post marketing surveillance, clinical trials.⁵⁷ For example, “Vioxx” was a pain killer which was effective for pain and the manufacturer tried to extend its market by trialling the drug’s effects on reducing bowels cancer risk. The study was called “APPROVe” (Adenomatous Polyp PRevention On Vioxx). The risk of polyps was reduced in this product (as it is in other anti-inflammatory drugs), however the trial had to be stopped due to the number of blood clots that the drug caused. The company that funded the

⁵⁶ A practice that occurred in Australia at the Chelmsford Private Hospital in the 1960s to 1970’s whereby patients were put into a prolonged comatose state by using Barbiturates and patients suffered great harms without benefits.

⁵⁷ Phase 4 of any clinical trial is discussed near the start of section 2.6.1.

trials did not disseminate these adverse findings. (Fontanarosa, Rennie, & DeAngelis, 2004). Academics in E.B.M. have shone a light on the futile government stockpile of anti-flu drugs that have minimal impact of the duration and severity of the flu. Such academics demonstrated that governments made large purchases of anti-flu drugs based on evidence provided to them from poorly designed or even ghost written “not so scientific” studies (Heneghan et al., 2014). Ghost writing is a process whereby typically a pharmaceutical company develops a research question, methodology and conducts “research” and then influences a seemingly credible person to publish the journal article in their name, when this person might not have even properly read the paper. By this process, clinical guidelines and influential studies may be influenced by industry (Wislar, Flanagan, Fontanarosa, & Deangelis, 2011) based on industry interests. Such activity provides examples of the misappropriation of science and the process of E.B.M., as what looks like scientific activity designed to promote effective health care was in fact a form of deception that served to promote corporate profit.

The journals used to disseminate research in the process of E.B.M. also openly demonstrate its fallibility. For example, one study suggests that one third of inpatient admissions are iatrogenic (Makary & Daniel, 2016) and another study reported that adverse drug reactions account for 3 % of adult hospital admissions in Australia (Roughead, Semple, & Rosenfeld, 2016). Other studies commonly quote figures of iatrogenesis to be 5-30 % (Atiqi, van Bommel, Cleophas, & Zwinderman, 2010; Garry et al., 2014; Lakshmanan, Hershey, & Breslau, 1986). Even manuals that detail the process of E.B.M. make it clear to readers how flawed much of current E.B.M. practice is, with much of what is now practiced in medicine is not based on readily appraisable evidence (John S. Garrow, 2007).

There are many examples of “medical reversal” (Prasad & Cifu, 2011) and “retractions” in the process of E.B.M. whereby of what seems “best available evidence”, 40 % of research publications are later proven to be ill-founded. This and other such evidence may support people opinions that the E.B.M. process is a weak paradigm which is not to be trusted. Notions of disease and health may be shaped by pharmaceutical company marketing to extend market share via “disease awareness campaigns”⁵⁸ (Greenhalgh et al., 2014). “Opinion leaders” (journals or individuals) may receive industry or career benefits, which might not be listed in their conflict of interest declarations (Moynihan, 2008). Such conflicted sources may be who E.B.M. clinicians “trust” for “reliable” information, such trust ought to be “qualified” (see chapter five⁵⁹) as by adopting a fallibilist attitude clinicians should realise that no system or process is totally reliable.

Those who support the process of E.B.M. recurrently expose ill-founded research and evidence, sometimes highlighting fraudulent activity conducted by those who have falsely claimed to operate under the guise of E.B.M processes or due to mistakes that those with the best intentions have made. A fallibilist attitude assists those guided by the process of E.B.M to seek to learn from past mistakes (Mamede, Gog, Berge, Saase, & Schmidt, 2014) in a similar manner to the aviation industry with the “Swiss cheese model” of quality improvement that I will refer to later. For example, many hospital units hold regular morbidity and mortality meetings where the clinical team is encouraged to openly discuss what they might learn from adverse clinical events to not only improve clinical knowledge but also to improve clinical processes. By people

⁵⁸ For example, the pharmaceutical industry “invented” a new disease “female sexual arousal disorder”, claimed to be treatable with sildenafil, and funded “research” into this area and attempted to have the disease introduced to diagnostic manuals (Moynihan, 2005).

⁵⁹ That is, qualified in the sense of being “limited” or “conditional” and qualified in the sense of being appropriately credentialed.

adopting a fallibilist attitude in health care, a case can be made that mistakes are not necessarily the fault of one individual alone, but that mistakes often are contributed to by the fallible systems that a person works in. A recent much publicised case of such meetings and following processes was the British case of Dr Bawa-Garba⁶⁰ who was involved in a case where a child died and the clinical team openly discussed the factors, apart from that one doctor's decision, that lead to adverse health care.

Awareness of this case and its aftermath, whereby international support was given to support Dr Bawa-Garbar, might encourage doctors to be open in admitting their errors, with the understanding that often such errors are recognised as being made in a context where the health system is set up to facilitate practitioners to find errors and adverse events, in ongoing attempts to develop processes to improve patient care. In adopting a fallibilist attitude, those who refer to E.B.M. processes ought to appreciate that mistakes can and will happen in health care - by referring to scientific methodology, they can seek to make the process of patient care safer, which in a sense is a self-correcting process. Alberts argued that science (the method E.B.M. refers to for much external evidence) is self-correcting and claimed that, "Instances in which scientists detect and address flaws in work constitute evidence of success, not failure." (Alberts et al., 2015, p. 1422)

In the context of the ideal process of E.B.M., the pillars of evidence that the doctor ought to consider are importantly the patient and their perspective and at times scientific evidence from sources such as the Cochrane Collaboration⁶¹ and reputable

⁶⁰ This case I will detail in part B of section 4.2

⁶¹ The Cochrane Collaboration is an international non for profit group of people who will not accept commercial of conflicted funding whose "mission is to promote evidence-informed health decision-making by producing high-quality, relevant, accessible systematic reviews and other synthesized research evidence." (<https://www.cochrane.org/about-us>).

journals that are both acknowledged to be fallible. Looking for mistakes, and for poorly conducted, conflicted or fraudulent research seems to be a natural fit for the processes of E.B.M. so those who use it while aware of their fallibility can seek to improve the entire process. In this manner co-deliberation (as discussed in the next chapter) ought to occur if a doctor and patient are to be guided by the ideal process of E.B.M. and are to try to improve on what they acknowledge is a paradigm that ought be successively reviewed and improved.

2.5 Error, chance, uncertainty and credibility in health care.

A patient or doctor could justifiably be certain about their belief in a health care decision; if it were the case that outcomes were certain in health care, that patients never improved or deteriorated where we could not assign a cause, and if errors never occurred. However, while we may justifiably be almost certain about the efficacy of certain health care interventions, the above qualifiers can plausibly be thought to hold, even in such cases. Patients and doctors may be more or less certain about the veracity of a belief and differ upon what value they attach to that belief. In a case of such differences, the fallibilist process of E.B.M. that doctors and patients can refer to, may be used to provide guidance as to what they can justify to each other is a well-founded health care related belief.

2.5.1 Error and uncertainty are inevitable in health care and should be accounted for in determining what ought to be considered as credible in health care.

There is empirical evidence in the literature that error and uncertainty are inevitable in health care. (Evans.M, 2004; Groopman.J, 2007; Montgomery.K, 2006; Rubin.S.B, 2000; Sox.H.C, 1988; Wolman.M, 2004). Groopman argues (Groopman.J, 2007, p.

152) that there is uncertainty in a clinician's mastery of current knowledge, and Wolman shows that there is uncertainty in the veracity of current medical knowledge, and uncertainty about how much personal ignorance or ineptitude come into clinician judgements (Wolman.M, 2004). Groopman encourages patients to share the therapeutic process as he claims that this will help clinicians in their care of patients by assisting clinicians to recognise their biases, since clinicians are liable to cognitive traps and biases that are evident in the literature.. One example of such traps and biases is "search satisficing error" (Groopman.J, 2007, p. 169) in which a clinician notes one abnormality and assumes that this is explanatory, and then stops searching for other lines of evidence that may lead to another diagnosis.⁶²

Uncertainty underlies every step of the ethical therapeutic relationship. Starting with communication (Evans.M, 2004), clinicians do not know with complete confidence whether they have appreciated what a patient's authentic beliefs or circumstances are⁶³, to advise a patient appropriately so that the patient may attain substantial understanding about their health care. Patients and doctors who utilise E.B.M systems might find it hard to be certain as to what is "best available evidence" in each clinical situation, partly because they ought to be aware of the problem that the available R.C.T. may have been conducted on a population which is divergent from the patient before them. For example, in the case of E.B.M processes that inform a patient and practitioner about how to treat a sprightly 90-year-old hypertensive patient, the data from trials on hypertension management might pertain to younger age groups, or studies that do relate to the patient's age group might not be relevant to a fit 90-year-old as such studies are based on inpatients or the institutionalised. Even if patients

⁶² Further discussion of biases and heuristics in section 5.8.

⁶³ And patients cannot be certain a doctor has understood the patient. Discussed in later chapter.

and doctors who utilise E.B.M systems think they have the “correct” diagnosis, they may have difficulty judging what is the best available latest evidence for further action or inaction, as guidelines merely guide a clinician and patient, and clinicians generally ought to be aware that guidelines might be developing and might be more or less relevant to their particular patient’s case. Also, in judging what is best evidence, practitioners and patients might err in their processes of logic as since arguably we are all fallible in the ways that we communicate with each other as is the process by which we appraise the evidence that we base our decisions on. E.B.M. processes developed by those who adopt a fallibilist attitude may assist doctors and patients in being guided as to a hierarchy of evidence, while also acknowledging that while many treatments are highly effective, there is still possible uncertainty as to what evidence is best in each situation and how to assimilate such evidence to each clinical situation.⁶⁴

If it is acknowledged that error and a degree of uncertainty are possible in health care, it might be imprudent for a patient to consider that a health practitioner is trustworthy, in cases where the practitioner makes unfounded claims of offering a *certain* diagnosis and/or cure. While some medical interventions have a high rate of success and appear to doctors and patients to warrant a high degree of certainty, in my experience as a clinician it is often hard to be unreservedly certain that my advice or beliefs are always well founded and are going to help a patient. For example, I might believe that antibiotics are highly effective for uncomplicated urinary infections. However, what I advise a patient is an infection that requires antibiotics might actually be mild cystitis that often resolves spontaneously with or without antibiotics. Furthermore, what is judged to be an uncomplicated urinary infection might be due to

⁶⁴ Further discussed in section 2.4.4

another condition, such as an ovarian mass. Also, in treating a person with a fractured arm, a doctor may feel certain and have a well-founded belief that the patient's arm is broken, because as it grossly displaced, however, if the doctor feels certain that after treatment the patient's arm will heal as expected, such a feeling of certainty would be less well founded.

It would be immoral for a health practitioner to claim that their *complete* confidence of cure is well-founded or to claim that a patient should just put all their grounds for hope in the practitioner's healing ability, as such claims are wrong because they are deceptive. It would also be unethical for a health practitioner to claim that their purported infallibility, or even near infallibility, ought to be taken as a patient's main reason to consider that health practitioner as worthy of trust. While it can be coherent for a patient to regard such a practitioner as worthy of trust on such grounds, a patient's trust in a practitioner should not be based on such a deceptive claim.⁶⁵

2.5.2 Chance occurrences or occurrences that cannot be accounted for ought to be considered in making health care decisions.

Cure may occur by chance (Wolman.M, 2004), and cure might occur both with therapies more guided by processes of E.B.M., and with therapies less guided by E.B.M processes. Something with a 1% chance of cure might work and a therapy predicted to have 99 % chance of cure might fail. Things might turn out well despite what are plausibly foreseen as risky or dangerous decisions or systems. Though Wolman didn't define chance, in this context the meaning of "chance" might be similar to "random", or even "coincidence". By "random" I mean that which pertains to a

⁶⁵ See chapter 5 for further discussion on trust.

supposed causal association that might, as far as we can ascertain, occur, or not occur through no process or system. That is, in a random process, no method or system *seems* to apply as to show us how something occurred. By coincidence, I mean at least two things occurred at similar times without the expectation that this would have occurred. For example, a person recovers, or worsens after taking a remedy. Recovery might occur after taking a remedy, however what caused the recovery might be a random process or due to causal relationships that we cannot assign explanations to. A patient's recovery might occur after taking a practitioner's remedy; however the patient's recovery might be due to factors other than the practitioner's remedy.⁶⁶ The patient's recover after taking the remedy might seem to the patient to support them in their belief that their trust in their practitioner was justified. What was a coincidence that the patient recovered after taking the practitioners remedy might be the basis of a patient's reason to recommend that practitioner to others as a trustworthy practitioner⁶⁷.

Epistemological arguments might be used to dispute the belief that relying on a chance or coincidence may form a well-founded basis to determine what/who is trustworthy. Gettier's problem (Gettier, 1963) is much discussed in epistemology and challenged the standard "justified true belief" definition of knowledge by a series of examples. Gettier's problem is widely quoted as a challenge to the account the claims that knowledge is a "justified, true belief". I recognize that Gettier's problem concerned what grounds knowledge, however in Gettier's cases the beliefs, that are used to ground knowledge are ill-founded. Trust in part requires acquiring beliefs as to who or

⁶⁶ For example, due to the placebo effect , or due to factors that have not yet been assigned as casual factors.

⁶⁷ However, though one person might find a practitioner trustworthy based on many factors that seem poorly grounded (such as a coincidence, on the practitioner's facial appearance, stature or tone of voice), basing a critical health choice on a coincidence that the patient's friend consulted a practitioner before the friend was cured, might be imprudent for a patient and those who depends upon the practitioner actually being trustworthy.

what is trustworthy. Such beliefs might be more or less well founded and/ or coincidence as occurs in Gettier cases. There are many examples of Gettier's problem. The original pertains to job recruitment, but another well know example pertains to a man driving past a county of (unbeknown to him) fake barns. The locals make barn facades that only can be discerned as fake when off the motor way. In one example, a man sees a barn and believes it is a barn. In fact, it just happens to be a real barn in this instance whereas all the other ones he has seen are fake. His belief is true, but it seems to be by chance that it is true and seems hardly to be a well-founded belief. Gettier's problems question if beliefs that prove to be well-founded by chance ought to be used to acquire knowledge. Many current epistemologists argue that such knowledge is not justified if attained through chance (Dancy.J, 2010).⁶⁸ I question the basis of an accurate assessment that something ought to be judged as being well grounded as trustworthy, if the beliefs that support the conclusion that something is trustworthy are derived by what the person who trusts feels is coincidence or chance.

Before discussing why, a patient *ought* to be cautious in basing an important health choice on possible coincidence, I will discuss the possible *imprudence* of such a choice. Though a patient might trust a treatment based on chance or coincidence it might be imprudent for a patient to accept treatment of a critical health problem based on the anecdotal evidence that the treatment worked for other members of their social network or worked by chance for someone else. Anecdotal evidence may make no

⁶⁸ This reluctance to accept knowledge based on chance may be contrasted with an epistemology of "Reliabilism" that was worked on by Alvin Goldman in the 1960's, whereby we view knowledge as based on justified true beliefs that we believe are attained on "reliable" methodologies and processes. Such an epistemology accepts "externalism" in that the processes accepted as reliable we accept, may be influenced by factors external to our control or even knowledge. This seems similar to the fallibilist position where we accept we may not be sure we know truth, but we endeavour to aim for processes that are more reliable or likely to achieve our hopes.

allowance for the fact that a person may improve without an intervention or simply due to other factors such as placebo effect. Such a choice might also harm others who care for them. A patient is prudent to at least consider novel possible assignable causes revealed to them by trusted health practitioner where they have seen none, or at least trust their health practitioner enough to consider alternative explanations that the health practitioner might bring to the dialogue. Anecdotal evidence of efficacy in health care though intuitively attractive, might be problematic, as the many variables that scientific method and E.B.M. processes attempt to control for (such as coincidence), might not be accounted for and the decision might not yield what a patient hopes for.

Could it be that what is perceived at present to be chance be due to factors that an agent is unaware of or has not thoroughly considered?⁶⁹ Indeed it might be that there are factors that lead things to occur by what we take to be by chance, as we appraise it now, that we are as yet unaware of but may become so in the future. In the future with additional information, we may look back and believe that something did not occur by chance. That is, when we assume that something occurred by chance, we accept that we do not know why it occurred. Our empirical knowledge or phenomenological or conceptual knowledge of an area may be incomplete and developing, and so we may mistakenly regard an event as a chance occurrence when its occurrence was not actually by chance. By adopting a fallibilist attitude we may recognize that we are uncertain in many areas and we also recognize that chance might or might not have played a role in some outcome's evolution.

Having argued that it is imprudent for a patient to make an important health choice by relying on anecdotal evidence I here turn to discuss whether it is morally *acceptable*

⁶⁹ Such as "confounders".

for a patient or practitioner to engage in healthcare without attempting to account for coincidence or chance? It may be argued that, as from a Rawlsian view point, health is a “unique good” as its diminution is often involuntary and may set the patient at a handicap compared to others (Rawls, 1999). Daniels built on Rawl’s work and made claims that disease can reduce our opportunities to flourish as compared to the opportunities that we would have had if we had not become ill. According to my reading of Daniels that I will not further analyse here, as poor health might diminish a person’s “share of normal opportunity range for his society” and “normal species functioning” (Daniels, 1985, p. 57) the state of health is a unique “good.” If health is a “natural primary good”(Daniels, 1985, p. 58) this is a consideration worthy of appraisal in considering what “good” we are aiming for with our health care and how we might attain such a good. It seems unwise to be reckless with a primary good and it seems plausible to hold that we ought to make wise and considered health decisions if we believe that health is a “primary good”. However, a patient might bring into dialogue a rejoinder to the claim that health is a primary good *for them* that must always be sought. The patient might reject this strong reliance on such cognitive processes as they strongly feel a sense of care from their trusted practitioner. Furthermore, such a patient might claim that it does not matter to them that others who care for them believe that the patient is being reckless or that patients’ health practitioner is properly believed to be offering highly implausible and ill- founded health care. Is it morally acceptable for a patient to choose a very implausible therapy based on a reckless decision or “feeling” that cannot plausibly be predicted to have positive health outcomes? A patient might say that, “I just know that I can trust health practitioner X to save me as I believe in following a whim or taking a guess on this matter.” “I just feel it’s the right decision”. Indeed, the patient might believe that care, as measured

by empathy and warmth of the health practitioner, and their ability to choose care based on their “feelings” not cognitive processes, are more important to her/him than is a demonstrably effective therapy as measured by physical measures. However, it is questionable as to what degree health care ought to be based just on a patient’s feelings or phenomenological experience of care, or on the efficacy of some treatment as evidence by “scientific methodology” that utilizes fallibilist principles ⁷⁰. The answer might be complex and non-binary in that care ought to be based on a spectrum of “affective” and “cognitive” factors, that I will later claim include what patients and health practitioners owe to each other as discussed in chapter.

2.5.3 Whose credence ought to matter in health care decisions?

Though I will not provide a detailed discussion of the epistemic literature at this juncture, differing people can have differing levels of “credence” in a belief. Some people might have less credence in the evidence that is derived from the scientific methods that part of the process of E.B.M. is guided by. By credence, I mean how certain someone is that the proposition they believe is true or otherwise. A person’s level of credence in X, might also be in part due to how much they value X. A person might have more or less “objective” or “subjective” ways of giving credence to a particular belief. More “objective” means of attaching value to a belief might be standardly described as referring to means such as “confidence intervals”, “p values”, or Bayesian decision theory to determine how much a belief is epistemically warranted in a situation. In brief, Bayes’ theorem is a mathematical equation used in many

⁷⁰ It is also contentious to claim that feelings arise without some form of grounding, belief or input from a person’s environment.

disciplines to decide how much one may trust that the new evidence presented has impact on the issue of concern. In a manner, those who come to use the theorem require a fallibilist attitude to use it, to the extent that they acknowledge their uncertainty in the limited data that they have and that they will at least consider that new evidence might bring more or less credibility to a belief. The theorem is supposed to allow us to calculate what weighting to give to the multiple variables that we must consider in coming to form a belief, while allowing for false positives and negatives in the evidence behind the variables. In a clinical setting as a doctor, I often struggle to be sure what all of the variables are, let alone which are most salient.

Believing that they are using a “more objective means”, a person might choose to give a lot of credence to a belief that is “statistically significant” as its “p value” is very low, thereby suggesting to that person that the event is less likely to have occurred by chance. A person might also feel more certain in a belief if what is observed is in a narrow confidence interval, whereby it is thought that there is narrow range in which an observed effect of the belief lies. In contrast by using a more subjective assessment of credence, a person may believe that standard empirical observation and ways of determining the importance of variables is less relevant to judging their credence in a particular belief, as their phenomenological experience or feelings about the belief are a more accurate way of assessing the value that they attach to a belief ⁷¹.

For example, for a person who is 40 years old with breast cancer and dependants, a 1 % increased survival benefit gained in using chemotherapy may seem of more value than for a 95-year-old who expects to die soon and does not want to risk adverse treatment effects. That is, whether a patient determines if they ought to use an “improbable” therapy, may vary in differing contexts based on the patient’s cost benefit

⁷¹ For example, of this see my reference to Gert Gigerenzer in section 5.8 .

analysis and means of determining credence. The person's assessment of the significance to them (and to the people they care about) of a probability varies, whereas the probability remains the same. The probability seems fixed, however the assessment of benefit and harms or relevance of a piece of evidence, changes in each clinical case ⁷².

While the numeric probability might be a matter neither patient nor doctor can dispute, how this evidence is to be applied in a health care decision is open to interpretation. In cases where there is awareness of the probability of various outcomes, a patient and doctor can benefit in using such evidence to weigh up how various probabilities apply to their case. How such evidence is discussed depends on the nature of the patient doctor relationship and the nature of what is hoped for in the patient's health care. How a doctor and patient give credence to beliefs might not be based on the same way of assessing evidence for all patients and all clinical situations as too many variables apply to each clinical case and to the unique patient. In the three pillars of the ideal process of E.B.M., practitioners and patients ought to co-deliberate upon not just empirical evidence but values and the patient's feelings. Practitioners ought to be cognisant that the significance of an agreed probability of harm or benefit of a therapy might have different significance for the patient as compared to the significance attached to that probability for the practitioner or for another patient. Conversely a patient reasonably ought to be cognisant that their practitioner might attach differing levels of credence to a belief than the patient attaches to that belief.

⁷² For any two individuals, a belief might be as equally "reasonable" as they both accept that good epistemic process and evidence warrant a belief, however each individual may judge a belief to be less plausible than another person based on what credence they give to a belief.

In cases of disagreement over what can be counted as salient evidence or what is a “credible risk” involved in a particular procedure, both parties⁷³ ought to appreciate that they have differing factors that influence what they give credence to. The determination of the significance of the other person, or what is owed to the other, might also reasonably vary for the practitioner and the patient. However, where both have agreed to engage in a model of the ideal deliberative doctor-patient relationship the practitioner and patient owe it to each other to determine what weighting a probability assessment is given in determining their credence, not just for clinical decisions but in deciding what to hope for as relevant to health and the doctor-patient relationship.

A patient might decide upon a therapy based on false or ill-founded beliefs as each patient may give differing levels of credence to differing beliefs. However, a patient ought to acknowledge that those who care for them might give differing credence to a patient’s fanciful or ill-founded beliefs and might attach differing significance to the evidence upon which a patient bases their health decision. In cases of “high stakes”⁷⁴ health decisions carers and patients ought to acknowledge that either party might give differing levels of credence to the view that a belief is ill-founded, fanciful or well grounded. In such cases, in a fallibilist schema of the three linked constructs, the health practitioner and patient owe it to each other to engage in co- deliberation to discuss why each of them ought to give more or less credence to more or less probable therapies and why one person might consider the grounds for a belief to be well-founded while the other appraises a belief to be ill-founded. However, debating the credibility of what is relied upon as evidence in a high -stakes health choice is only

⁷³ That is, in the context of the schema of the three linked constructs.

⁷⁴ By using the words “high stakes” I refer to for example, “life or death” decisions, or situations where those involved might be greatly impacted or at great risk.

part of the reason patient and doctors ought to attend to one another's beliefs. The patient's social context and the implications for what they give credence to with respect to their health also ought to be open for co-deliberation in the I.D.D.P.R as the patient should not reject that they ought to not disregard those whom they have agreed they have a "moral relationship" with (see chapter 2).

Both doctor and patient ought to be aware that they are not infallible in their attempts to bring more certainty to the patient's future. They may use tools such as ones based on Bayes' theorem to take into account of as many variables and uncertainties as they can, to form justified true beliefs, but also may accept that error could occur at any stage in their belief formation. I defend a claim that it is morally justified to accept the inevitability of a degree of chance in the epistemology of health care, and that ethical health care aims to be honest in admitting to this chance and in trying to identify health interventions that may be in fact due to chance or factors not yet assigned as being important. In this manner practitioners and patients who are guided by processes of E.B.M. may gain a better understanding of a health outcome that might have otherwise been said was due to chance. Where possible and appropriate, doctors and patients ought to try to find out if a health condition will resolve without treatment, and where possible, attempt to bring what is believed to be a chance down to as low as possible, to yield effective care in the interests of the patient. It might seem to another person arrogant for a doctor or patient to be adamant that they are making the right choice for a health care decision that they claim to have made without any consideration for appraising evidence external to what they feel and that the simply "feel like taking a chance". The honesty of admitting to others and ourselves that our certainty in matters of health care decision making may have a degree of reservation is a pragmatic,

fallibilist view.

2.6 Fallibilism and humility

Fallibilism should be acknowledged in any system of belief in health care, as there is ample evidence that health practitioners and patients are all fallible in arriving at the diagnosis (Berge & Mamede, 2013; I. A. Scott & Crock, 2020; Zwaan, Thijs, Wagner, Wal, & Timmermans, 2012) and in gaining an accurate comprehension of the natural history of illness and of what are effective health care interventions (Atiqi et al., 2010; Friedman et al., 2001; Garry et al., 2014; Roughead et al., 2016; Wolman.M, 2004). In the same way that the human body and mind is fallible (Popkin & Maia Neto, 2007, p. 235; K. R. Popper, 2002) and departs from "normality" or "fails" so readily, so too are the health practitioners and health systems that they work in. Importantly, health practitioners and patients might be equally in error, and regret decisions made or be self-deceived. It is plausible to hold that as all earthly nonspiritual things eventually change, degrade, or undergo senescence and die, we may not be absolutely sure at what time our beliefs might also prove implausible and change.

We may change our beliefs in a number of ways. Put simply; we change our minds, not just epistemically and in what we feel, but in moral matters. For example, George Wallace, former Governor of Alabama initially came to power on a racist, segregationist platform in the 1960's, then by 1982 won 90 % of the "Black" vote as he apologised to the civil right activists and black churches and asked for forgiveness (Cornish.A, 2013). Awareness that we change our minds in what we hope for and believe in, has direct impact on clinical practice.

In my clinical practice, if I consult a woman who seeks abortion advice, it is my routine informed consent practice to (where possible) respectfully suggest that no decision is ever 100 % certain and we often make a choice at the time with the best information that we have. I broach this subject at what is often an emotionally charged time, as I suggest that if in the future, she regrets her decision, or understandably has a level of grief over her predicament and the decision she is forced to make, I plead with her to remember in the future that she is doing what she considers is best now. She makes her decision with the best information she has at the time. I do this as, in my clinical experience over years, some women have anniversaries of the loss, or a birthday that never was, or has grief that they never subsequently have a child and missed their chance even though the past circumstances were adverse. In this way the informed consent process imagines the future self (Parfit, 1984) and attempts to avert potential future grief. A woman may change her mind in the future and consider her choice to abort a mistake, but she makes the decision now as best she may, aware that she may regret her decision in the future.

What we provisionally believe now we may not in the future. Hillary Putnam's characterisation of fallibilism suggests that,

“There is never a metaphysical guarantee to be had that such-and-such a belief will never need revision” (Putnam, 2004, p. 152). A fallibilist may have beliefs but readily accepts that such beliefs may change. Importantly for my thesis, Christopher Hookway provides an account of fallibilism which claims that a fallibilist does not search for the truth, but seeks for the most well-founded tools that benefit enquiry to achieve goals as best the agent may.⁷⁵

⁷⁵ The searching for the most effective and accurate tools that benefit enquiry to get to goals, can also be seen in how those who use the process of E.B.M attempt to develop the checks and balances to the overall process in an attempt to improve patient care.

I have asserted that we can pursue goals without having a capacity to identify with ‘absolute certainty’ whether we have achieved them. We may believe that we have reliable indicators of success, but these may be fallible or inconclusive. Often we hope that things will see us right, but we have no guarantee of this (Hookway, 2012, p. 17).

To further illustrate this point, Hookway argued that by adopting fallibilism we may have no need to seek truth itself but that we seek “effective cognitive instruments” (Hookway, 2012, p. 3) to achieve outcomes that we can never be sure we have attained. In health care that is based on a fallibilist attitude, we might generally consider a treatment reliable and effective, but possibly fallible. In health care that embraces fallibilism, practitioners and patients are not certain that a health treatment is 100% reliable or that their construal of what is the healthiest option is the always the healthiest option in every circumstance. Though indeed, in many aspects of health care, it might seem apparent that one health choice is best for health. For example, it might seem apparent to all concerned that a major heart attack is best treated (while acknowledging that a patient might not survive with the “best care”) with routine acute care rather than, for example a homeopathic therapy alone. In some aspects of health care, where psychosocial aspects of care seem more important to patients and health practitioners, it might be less certain what is more effective form of care, or what the aim of health care ought to be. However, in utilizing a fallibilist system of appraising evidence such as I claim processes of E.B.M. rely upon, such practitioners and patients might feel assured that they have referred to each other and to the “best available epistemic tools” in giving credence in what to believe is effective health care.

By adopting a dogmatic attitude, a patient might accept treatment from a practitioner for the patient's testicle cancer while saying that they trust that practitioner so much that they believe that they have no need for informed consent that requires consideration of other evidence, other than the strength of their feeling of trust in the practitioner. However, following one health belief or practitioner with a dogmatic attitude is not advisable as though a patient can feel certain that this is the right path, it is not always 100% possible that the patient or practitioner has appreciated all that is well founded or salient in a health choice. If practitioners and patients ought to have a professional relationship that is governed by co-deliberation (Chapter 3) than both parties ought to be open to attending to each other's beliefs. By adopting a fallibilist attitude, the practitioner and patient have at least some degree of opportunity to consider salient, plausible evidence that might consider. Standard notions of informed consent (Beauchamp T.L, 2001) fit well with the co-deliberative model (chapter 2) and some accounts of informed consent suggest that generally patients ought to have a minimum level of information before undertaking treatment. One of the reasons for patients to require informed consent for treatment is that a treatment might fail. If a treatment fails through no negligence of the practitioner, not only is responsibility for the failure to some extent shared between the patient and the practitioner, but the patient might well be more prepared for treatment failure. A health practitioner ought not to treat a person based exclusively on the patient's trust of the practitioner and what the practitioner prescribes as the practitioner ought to accept fallibilism in health care, and it would be dishonest of them to claim a "guarantee of cure".

From a virtue ethics standpoint an argument might be developed that fallibilism is a virtuous form of epistemology in health care, as there is virtue in the humility that fallibilism requires to flourish. This presupposes that intellectual humility is a virtue,

and that being virtuous is part of professional ethical care. Further discussion of the virtue of humility in health care is given by Judith Andre (Rubin.S.B, 2000) who argues for an account of humility that she claims is necessary for good clinical practice. From Chapter 4 she introduces,

"the moral challenge of accepting our fallibility and at the same time struggling against it" and she argues that "humility is necessary to be compassionate to oneself" (Rubin & Zoloth, 2000, p. 102) in the setting of accepting and getting debriefing as one inevitably makes errors in clinical work.

Norvin Richards claims that,

"humility is a virtue that not only lets us see our mistakes, but simultaneously [enables us to] to live with them and try to minimise them" (Rubin & Zoloth, 2000, p. 67). Joel Frader in the same text writes that,

"Uncertainty can be acknowledged with humility, and can be responded to more clearly and honestly...One's attitude to one's mistakes is central to moral life, in a way that is as yet poorly articulated".(Rubin & Zoloth, 2000, p. 168)

Frader's claim is that if we accept humility as a strength of character, not an admission of weakness, we are more likely to seek out mistakes and form systems to rectify them.⁷⁶ Health practitioners are virtuous in seeking to improve care for current and future patients by adopting a fallibilist approach, by being humble in their attitude.

Certainly, in the opposite state of affairs it would seem a less benevolent system, were arrogant or dogmatic health practitioners to consider themselves or their remedies infallible. If we consider that the vice of hubris is opposed to humility, we might see more reason to think that humility is pivotal to ethical health care. From

⁷⁶ While these above claims would require further social research studies to have more credibility for some people, these claims do seem at least to be plausible.

history or philosophers as diverse as Spinoza to Bernard Williams, we see human hubris as a leading source of forming unjustified beliefs and leading to a nemesis of ethical deeds as occurred in the mythology of the ancient Greek Gods. Many of the Greek tragedies had tempestuous Gods setting up mischievous and arrogant behaviours in how they deal with themselves and mortals with tragic consequences. Intellectual arrogance has the effect of stifling further debate and sets up the arrogant one as in some way not needing to learn more or to question more what they believe. Where it is plausible that further understanding of a matter might be possible, Intellectual arrogance (as compared to intellectual humility) is ill founded in its assumption that there is a finitude to enquiry, when in fact there are virtually always new ways to understand something and learn more; “Anquora Imparo”.⁷⁷

A variance of intellectual arrogance can be seen in some current world political leaders and is discussed by philosopher Michael Lynch (Lynch, 2018) who writes of “epistemic arrogance”, where there is a refusal to give “recognition respect” (Darwall, 1977) to others that they may be able to further one’s understanding. Quoting from Lynch,

“The epistemically arrogant are those whose passionate intensity flows from the conviction that they have it all figured out; that they know it all, that the light of truth shines within them” (Lynch, 2018, p. 184). Furthermore, Lynch says that not only do the epistemically arrogant fail to be “open minded” and accept their own fallibility but they also “fail to assign epistemic blame and credit appropriately” (Lynch, 2018, p. 285). Such a person refuses to accept that epistemic credit can come from those around them but believe that “when things go right” this is all from their genius. If errors occur, Lynch claims that the arrogant will blame and attack others for error as they are

⁷⁷ Anquora Imparo is the motto of Monash University and may be translated as “I am still learning”.

in their mind, too clever to make mistakes. In extreme cases of arrogance, truth is sacrificed to uphold the epistemically arrogant person's heightened sense of self-esteem. Lynch claims that arrogance is disrespectful to others and has deleterious effects on trust and respect for truth. If we understand ethical behaviour as involving in part, respect for others by upholding truth and integrity, then rejection of fallibilism may lead to arrogant attitudes and unethical consequences.

Whereas Lynch writes that the arrogant may think themselves great, in order to maintain or exert power over others, the opposite of arrogance is powerful. I claim that humility yields power, to say "I don't know, or I am not sure". It is important to this thesis to hold that it is plausible that there is power in admitting that one doesn't really understand something and has to gain more information or consider it for longer before one forms a belief.⁷⁸ There is power in having time to deliberate on a matter and seek more opinions, reflect on what others have said and generally "look things up". In this manner, patient and doctor might have an opportunity to make more informed and possibly prudent health care decision for the patient. Acknowledging the work of Tversky and Kahneman (Kahneman, 1982; Tversky & Kahneman, 1974) it seems to me that we must consider our psychological fallibility in making judgements, and we are prudent to be humble, and attempt to learn how we fail in order to improve the accuracy of our judgements. Humility can bring a powerful motivation to improve and better ourselves that hubris would have us belittle. We deny our weaknesses at our peril, not only in battle, but in learning how to best form judgements.

Hubris, to think oneself infallible (or even near it!) seems to curtail the chance for reflection, consultation and mentoring as with such a delusion, there is no opportunity or need to reflect with others or to dwell on beliefs. A hypothetical practitioner who

⁷⁸ A belief that may change with more deliberation or as more evidence presents itself or is reconsidered.

believes that they “just know what’s best” or that their therapy is infallible might not see reasons for the doctor to seek to understand how a patient thinks or understands their condition. Best health care might be precluded by the dogmatic practitioner, who for example says to a patient; “Just trust me I’m a doctor”. Such a hypothetical doctor is not properly considering the individual patient (as the doctor might believe that the doctor is the basis of therapy), and thus might not come to an accurate diagnosis as the correct (individual patient) information is not sought and best management options might be missed. Not only is the dogmatic practitioner showing hubris, but such a hypothetical practitioner is not benevolent as the patient is thereby deprived of opportunities for more effective care that is relevant to their unique situation.

A famous example that seems a case of hubris and of how a doctor ought not to treat a patient is the 1988 New Zealand case of Herbert Green (S. Coney, 1988) who was the focus of the subsequent Cartwright inquiry.⁷⁹ Though the facts are still debated as to his motivations, Green was a leading gynaecologist who believed in an ill-founded conjecture that certain changes to women’s cervical cells do not progress onto cervical cancer. He went against mainstream international medical opinion and treated women with severe cervical cell changes by observing the women with repeated biopsy procedures or in some cases just less accurate “Pap Smears” while the women were unaware of the fact that they were participants in Green’s “unfortunate experiment” (S. Coney, 1988)..

In her subsequent Inquiry, Judge Cartwright found that Green behaved unethically as the women needlessly suffered due to Green’s conviction in his non-mainstream view and additionally that patient informed consent standards were ignored by Green as patients were either not aware of their condition or were not informed of the “usual

⁷⁹ This enquiry focused on events of the previous approximately 20 years

medical care". It is possible that Green had "search satisficing" error (Groopman.J, 2007, p. 169) as he dismissed his own data that came in over the years which was contrary to what he sought to prove. Green sought to prove that the gradual transformation of cells seen on some women's sequential cervical samples, was not associated with some of these women developing invasive cervical cancer. Green's unethical behaviour seems a clear example of hubris in that he did not inform his patients of their condition and because Green sacrificed patient's care (and lives) for his belief or reputation. Green was dishonest to the women involved in not informing them that they were part of his experiment and so were not receiving what was by then generally regarded as the "best" care that they reasonably may have expected of the head of the "National Women's Hospital Cervical Cancer Unit" at a major teaching hospital. Green ought not to have flouted the standard of shared decision making that was the antithesis of the fallibilist model of the "I.D.D.P.R". Hubris might be fertile ground for dishonesty not only because it might allow for patient deception (as in Associate Professor Green's case) but as a practitioner who demonstrates hubris might be less likely to say, "I am not sure" and simply proceed with advice so that that they do not display doubt. If a health practitioner believes that they are "definitely right", or sure of cure, the practitioner's certainty is a property of the practitioner and may be not only be misguided but a fantasy. Such a fictitious belief of being an "infallibilist" practitioner can readily lead to deception as the health practitioner is unable to say "I don't know"⁸⁰. This is due to their ill-founded denial that uncertainty about decisions and many beliefs and is inevitable in health care that is based in fallibilism.

Generally ethical doctors owe it to patients to be honest and admit at the onset of a therapeutic relationship that despite their best endeavours, doctors can fail. I might be,

⁸⁰ I remind the reader of Montaigne's argument that dogma does not allow us to know what we do not know.

and hope I am, a generally reliable and trustworthy doctor; however, I am fallible and ought to recognize that I am fallible and make allowances for my possible failings. At times patient have said to me “You’re the doctor. I just trust you to decide for me Dr. John.”⁸¹ However, I owe it to my patients to make it clear that though I am honoured by their trust and do my best to be trustworthy, I am fallible. As an ethical doctor I ought to acknowledge the power of my sense of humility as a means of improving my ability to care for patients. Even if as an expert doctor I have a high degree of certainty about some clinical matter, the basis for my belief might be factually uncertain, as I acknowledge that I am fallible.

2.6.1 A discussion of the level of evidence a fallibilist health practitioner can accept before recommending to a patient a contentious health practice.

It is possible to ethically practice acupuncture, by practicing in a fallibilist attitude (as detailed above and in the literature (Weintraub.R, 1993)), as I admit to myself and others that I might be mistaken in my disbelief, or in my doubt in the efficacy of acupuncture. Who am I to be sure that a patient is misguided or in some way duped into believing that they are improved by acupuncture? As a doctor who tries to adopt a fallibilist attitude and aims to be guided by E.B.M. processes, I am intellectually humble, at least with respect to my medical beliefs! A patient might say that they feel that they have less pain after acupuncture, or that they feel cared for by the acupuncture practitioner.⁸² While considering the mechanisms of acupuncture I cannot

⁸¹ Such a sentiment is similarly expressed as “You’re the doctor. I will do what you tell me to do.” (Devereux, 1992, p. 1410) .

⁸² As it may be hard to contest what some one feels, even if that feeling arises from a delusory source such as feeling of choking when one is not or feeling in love when one is merely infatuated.

be completely sure, that there are *not* “lines of Chi” along the body and that “tonifying” such “meridians” in certain ways alleviates certain conditions. It is a fallibilist position to state there is much in science and medicine that is unknown, and with guidance from the process of E.B.M. doctors and patients strive to improve what we provisionally work with, in their attempts to reach health goals. In some circumstances it is ethically justifiable to practice a therapy⁸³ that might be therapeutically active over, for example a placebo, with a view to having this therapy more rigorously appraised by E.B.M. processes on condition that; (a) the therapy is subject to mainstream E.B.M. processes of scrutiny and revision, (b) patients are fully informed of alternatives, especially where if available effective alternatives and known harms and benefits (c) that patients / health practitioners understand that the under investigated therapy is probationary, in a way experimental medicine, and (d) care that is known to be effective is not deferred and economics are fair and divulged.

Motivated by other patients telling me that they feel efficacy of care with acupuncture, it may be one of my lines of enquiry that I share with a patient, to consider that there is growing evidence for acupuncture’s efficacy regarding certain health issues. At conferences I learn of an increasing number of papers in mainstream journals that support acupuncture (Lam, Galvin, & Curry, 2013; Vickers et al., 2012) and my anecdotal success in using acupuncture and patient preference seems to provide some grounds for my use of acupuncture as a probationary therapy. However, such use of acupuncture is conditional on the understanding that I may be using an open placebo⁸⁴ if I tell patients that I am not sure either way of acupuncture's efficacy and that the evidence of acupuncture’s efficacy is not conclusive. I may express to patients

⁸³ Such as acupuncture.

⁸⁴ By open placebo, I mean use of a therapy, where the therapeutic effect is not in the therapy itself, but in the process of therapy and both patient and practitioner are aware of this process, so no direct deception occurs.

that I use acupuncture as I think that aspects of acupuncture practice are gaining increasing credible evidence as appraised by E.B.M. processes. Though trials are under way, evidence for the efficacy of acupuncture is not as robust as it is in many treatments that have been more rigorously appraised by processes of E.B.M. Indeed, I acknowledge to the patient that much of what medical doctor's practice is thus far itself unsupported by robust evidence⁸⁵ however I still consider (and the worldwide consensus of other practitioners who are guided by E.B.M. still consider) that such care is the safest effective current alternative.

Standard medical practice provides examples where health care practices are adopted "before all the evidence is in" with at times positive and at times negative or neutral health outcomes for patients. A positive example might be that of the trial "safe injecting room" in Richmond, Melbourne.⁸⁶ I understand that in this circumstance, though evidence supports the use of such facilities overseas, we do not yet (at the time of writing) have knowledge of what impact the facility may have in this community, and so we commence the therapeutic intervention and study its effects longitudinally.⁸⁷ Many examples come to mind of negative effects of clinicians being too rapid in their uptake of a therapy. For example, "Adifax" was a widely marketed medicine prescribed to increase satiety to assist patient with weight loss. Only in its phase 4, post-marketing surveillance phase was it realised after the drug was consumed by thousands of patients, that the drug was linked to heart issues (Dahl, Allen, Urie, & Hopkins, 2008). In the release of any new drug, various phases of testing of the drug's safety and

⁸⁵ And there may be evolving rankings of evidence (Guyatt et al., 2008).

⁸⁶ "A safe injecting room" I understand to be a facility where people with dependence on injectable drugs are treated as people with a health rather than criminal issue and provided with clean needles, sharps disposal bins and supports aimed at harm reduction.

⁸⁷ We might seek such a study to learn what the impacts of the new injecting room are on the people who inject, how real are local resident concerns, for example that their security might adversely impacted or their house value might decline, or other variables that are less apparent.

efficacy occur, with phase one trials being limited to twenty or so people, phase two and three trials involving larger numbers of intensely monitored people, however it is in phase four trials, after drugs are marketed and large numbers of patients “try out” the new drug that (fallibilist) E.B.M. guided processes continue for years to monitor for unexpected outcomes. This process attempts to assist doctors and patients who adopt a drug early after its release to market, to learn if trends are emerging of adverse events around the world.

Interestingly at times doctors are not “early adopters” and have not changed their practice even when credible evidence is widely published. Examples of doctors being slow to practice what E.B.M processes offer as more credible evidence are plausibly seen (a) in the way that doctors are not always consistent in following guidelines, for example in antibiotic prescribing, or (b) due to lack of awareness of, or acceptance of plausibly conclusive evidence. For example, the background to the formulation of the Cochrane Collaboration logo - described earlier – is illustrative of doctors being slow to adopt the use of steroids in premature neonates despite multiple sources of evidence that warranted change in clinical practice. Similarly, doctors were initially slow to uptake the use of medicine to dissolve clots in the brain in the acute management of some strokes, (Leira, Pary, Davis, Grimsman, & Adams, 2007) whereas now major centres have urgent systems to treat stroke victims.

As processes of E.B.M. have erred, perhaps doctors who claim to be guided by processes of E.B.M. might take themselves to have a plausible justification to try modalities such as acupuncture on the basis of the observation that doctors have in the past, been slow to appraise or put into trial practice treatments that were later widely viewed by science as the start of a shift to a new paradigm to follow. In addition, the observation that some doctors have been (often imprudent) “early adopters” in

prescribing a new drug before comprehensive evidence of harms/benefits is available, does not give credibility to similar mistakes being made in the early adopting of a novel therapy that is not being scientifically appraised. However, doctors' past mistakes in imprudently adopting a new drug too soon may in part be due to the (fallibilist) belief that negative evidence might be wrong, or conversely, that early evidence is possibly the start of a new "paradigm shift". Indeed, from a fallibilist perspective a fallibilist acknowledges that evidence might become more or less credible as our beliefs change or as new evidence is appraised.

Health practitioners might be anxious for their patients to not "miss out" due to what in the future may be seen as their clinician's over cautiousness. On the other hand, practitioners might be overly anxious about some remote possibility of an unexpected contingency eventuating from a novel therapy that might greatly harm a patient. An aspect to the claim that uncertainty of the facts is inevitable in health care pertains to the "precautionary principle". An element of this principle is seen in health care with the application of the bioethical principle, "First do no harm". In cases where decisions might be debated, a prime consideration if this principle is applied, is to do no harm; to proceed with caution, or act to avert harm. A commonly cited definition of the precautionary principle is said to be,

Where there are threats of serious or irreversible damage, lack of full scientific certainty [about such threats] shall not be used as a reason for postponing cost-effective measures to prevent environmental degradation (United-Nations, 1992; Viñuales, 2015, p. 635).

We see the precautionary principle also applied in the case of world climate change where commentators such as Rupert Read (Read & O'Riordan, 2017) argue that

though climate change sceptics may exist, to ignore the large body of science is so risky and the consequences are so grim that if we do not act now we may cause a disaster in the future. By this argument, to wait for all the data to be verified by science is imprudent as “we must act now” even with uncertainty about what is more probable, as the consequences of procrastination are foreseeably so disastrous⁸⁸. Considering the implications of the precautionary principle, one criticism of this principle might be that doctors who await a well-developed E.B.M. process of appraisal of a therapy, can in the meantime not be sure how much evidence is enough evidence for a novel therapy to be cautiously practiced or an for an old therapy to be justifiably rejected. Indeed, a similar criticism could be levelled at fallibilism in general, in critiquing how people who adopt a fallibilist attitude come to determine what type and amount of supportive evidence is enough in order for the fallibilist to acknowledge that a belief is credible. Furthermore, without certainty as to when a therapy becomes acknowledged to be “evidence based”, it might seem reasonable for patients to challenge why they ought to trust such a system of appraising evidence that can’t even stipulate precisely when there is enough evidence for a belief to attain the status of being considered by those who utilise E.B.M processes as being “credible evidence”.

In defence of fallibilism and the use of processes of E.B.M. against such concerns, we may return to an account of fallibilism where, as practically speaking decisions must be made, a fallibilist can (qua fallibilist) form a belief or a disbelief, without being certain that the belief is completely well- grounded. In addition, fallibilism need not be

⁸⁸ Similar arguments applied to bans on cigarette promotions from the 1970’s. Cigarette manufacturers promulgated information to sway public opinion that the then unproven harmful effects of smoking were uncertain. Governments went ahead with marketing restrictions on the sale of cigarettes despite such “robust proof” using the precautionary principle. Similarly, the paramedics do not await more data for the perfect definitive treatment of chest pain but act on what they now have. Ebola and Sars Cov 2 vaccines were initially released before undergoing the usual scientific assessments, were cases where to avert a perceived calamity we accepted uncertainty in our science as at times we reasonably believe we must act with degrees of uncertainty in some settings of health care.

“global” as, for example, a fallibilist might utilize norms of logic such as deduction or induction. By global here I mean “all things”. That is, in adopting a fallibilist attitude I may recognize that to appraise situations I ought to use norms of logic, such as that something cannot be its opposite (e.g black and white) and itself at the same time. Further, a fallibilist might have a high degree of certainty in matters of morality or spiritual matters but recognize that in matters of health care we are more fallible. As a fallibilist I acknowledge that in many situations I cannot always define at what point a belief can (qua fallibilist) be probationarily accepted or rejected. In being guided by E.B.M. processes as a doctor, I recognize that it is not always clear at what precise point there is enough evidence for me to adopt or reject a health-related belief. The process of E.B.M might be developing general rankings of levels of evidence (Guyatt et al., 2008) but it is up to the patient and I to determine what evidence we give more credence to. In contrast, a dogmatist will tend to be certain when they have enough evidence; and that is when a belief aligns with their dogma. But can a dogmatist be 100% sure about why they have come to accept evidence to form a belief, other than perhaps to say, “They just know” or perhaps “it just came to me” or “It is a strong gut feeling”? In some forms of dogmatic faith⁸⁹, judgements of what to believe are made with the person in question dismissing the possibility of understanding how they come to that belief⁹⁰. A dogmatically held belief might lead a person to say that they ought not to appraise how they came to have strong credence in a particular belief as they hold that to do so is to doubt the core of their accepted dogma and that there is no point in appraising this as they are certain that they cannot gain further understanding. In this manner, the possibility to doubt and thus reflect on a belief might be reduced.

⁸⁹ See section 2.6.5

⁹⁰ See 5.10 for this discussion.

For example, an infallibilist senior doctor on a ward round, might berate a junior doctor for doubting the senior doctor's "clinical acumen"⁹¹ that the senior doctor believes that the junior ought to respect and not question. Further discussion is shut down by the senior doctor as the rules of the ward round are that junior doctors ought to believe in what the senior doctor says. The junior's respect for the senior might be such that the junior believes that they ought to not distrust the credibility of the senior's acumen and ought to just accept what the senior believes. However, by not allowing for doubt and reflection about clinical beliefs, the junior clinical team might be complicit in not acting in the patient's best interests. The team's feelings of reverence for the senior doctor whereby they do not question the senior's beliefs might come at the expense of co-deliberation upon what might be the most effective and safe care that the clinical team owes to the patient.

In adopting a fallibilist attitude, a person seeks for ever better cognitive tools that seem most likely to direct them to well-grounded beliefs. The fallibilist and the dogmatist might appraise the same evidence, however the property of credence that each gives for such evidence resides in the person, not in the evidence. In many situations there is not a precise point at which one can determine when "there is enough evidence" as plausibly people interpret how evidence is used based on many factors other than just the evidence that we might appraise in co-deliberative relationships. As later discussed, what is considered "enough evidence" in those who are guided by E.B.M. processes, is determined by a process of dialogue based on processes of assessing evidence that is being developed over time by many people. Furthermore, as I later claim, in the fallibilist ideal deliberative patient doctor relationship, there ought to be the possibility for dialogue about how each person

comes to give varying credence to evidence.

Unlike a Pyrrhonian sceptic, a fallibilist might utilise certain rules of logic or “numerical facts” (such as one plus one is two), or a fallibilist will cross the road looking out for not being hit by a bus. In this manner adoption of a fallibilist attitude need not be global in all that is appraised. A person’s fallibilist attitude need not be global in what is construed as required to function. “Practically” if I seek to cross the road safely, I ought to attend to my senses and look out for traffic. I ought to attend to and trust in my senses and have some form of cognitive appraisal about what is around me rather than solely rely on a chance that I will cross the road safely. The term practical in this context refers to “what seems to work”. This does not refer to accepting that what has worked in the past will, work in the future. Nor does the word “practical” refer to some suggestion as to what is construed as “common sense” that might be even less easy to define and be subject to promulgation of outdated incredible beliefs. The practicality of fallibilism refers to using beliefs that seem to work at the present time, with the information that we have now.

Though a practitioner who is guided by a fallibilist E.B.M model has no arbitrary definable point at which she/he acts on a belief, or thinks that such a belief is practical or impossible, the practitioner still ought to make decisions guided by co-deliberation with others. By a practitioner or patient adopting a fallibilist attitude, others’ opinions may be sought or listened to, thus showing respect for others who might be impacted by a patient’s health decision. It is often practical and prudent for patients and doctors to listen to the ideas of justifiably trusted others or those who are impacted by a health choice. The fallibilist, E.B.M system of giving credence to beliefs is in a sense “messy”⁹² but it seems to have produced results and keeps making progress in helping people

⁹² See section 2.4.4

overcome obstacles to their health while allowing for the consideration of others. A doctor's acknowledging to a patient that acupuncture might be worth trying when the doctor is unsure of acupuncture's merits, demonstrates to the patient that the doctor is prepared to listen to the patient's ideas and to discuss beliefs that the doctor has not yet appraised or given much credence to, yet will consider.

If a patient wants to use acupuncture, then perhaps similar considerations to the ethics of clinical trials may of be relevance here in that the patient and clinician may be proceeding with a therapy that is more uncertain for the patient or clinician than for others. To quote Freedman,

The ethics of clinical research requires equipoise-a state of genuine uncertainty on the part of the clinical investigator regarding the comparative therapeutic merits of each arm in a trial. Should the investigator discover that one treatment is of superior therapeutic merit, he or she is ethically obliged to offer that treatment (Freedman, 1987, p. 141).

Acupuncture is most plausibly ethically justified (with conditions as per section 2.6.1) by health practitioners and patients using acupuncture in the manner of an experimental therapy when the processes of E.B.M. have not been shown to provide safe and effective care that is acceptable and relevant to the patient. In the discussions of the ethics of clinical trials, great value is placed on the matter of patient informed consent, with guidelines highlighting the importance of patients being able to understand potential harms and benefits of a trial treatment that that might be unknown (National, Medical Research, Australian Research, & Australian Vice-Chancellors, 2007). Particularly if effective care is available with minimal risk, a trial may not be

ethical if effective care is delayed or denied⁹³ or if a risky novel therapy is tried. Caution must be taken that the patient does not have a ‘therapeutic misconception’ that their care is the primary concern, when in fact the advancement of knowledge, or a health system’s ideals is more the dominant purpose for trial treatment.

A final possible argument I discuss that might be used to justify the use of some modalities such as acupuncture can be represented as follows. Even if scientific evidence of acupuncture’s efficacy for an illness is not as available compared to therapies more robustly supported by E.B.M. processes in a particular condition⁹⁴, “the absence of evidence may not mean that the therapy does not work, just that there is no evidence that it does; i.e., “lack of evidence” is not equivalent to “evidence of lack”(Levy et al., 2015, p. 206). This argument could be reformulated as claiming that,

“lack of evidence of efficacy is not equivalent to evidence of lack of efficacy....” Which in turn may read as “absence of evidence is not evidence of absence” (Pickering, 2015, pp. 546-547). For example, a planet may not be visible with our best instruments and so we lack empirical evidence for what our theorems or imaginations tell us must be out there; we just have not looked hard enough or developed sensitive instruments to verify our theories. The planet, in standard scientific terms, exists in our imaginations but not in reality⁹⁵. However, as I have and will argue, we generally accept that we ought not to adopt a health practice based on imagination or fantasy or theory alone.⁹⁶ I ought not to be allowed to purport to heal people with what I believe is Kryptonite as I am superman, even if I claim that just because there is no evidence

⁹³ And the matter of equipoise is not contentious as E.B.M. processes have clearly effective therapy that will not be effective if deferred and disease goes past a certain stage.

⁹⁴ Or also in a condition where E.B.M. processes have not yet been developed.

⁹⁵ With the possible exception that we might adopt a post-modernist phenomenological account of reality.

⁹⁶ E.B.M. places “mechanistic reasoning” as *one* aspect of evidence to consider. People guided by processes of E.B.M. should try not to solely rely on theories to justify a therapy but corroborate theories with other sources of evidence. For example, it made sense that giving a child with fever paracetamol would reduce the chance of febrile convulsions for that child, however such practice proved in effective for that purpose, and has harms. See; <https://www.nps.org.au/australian-prescriber/articles/paracetamol-overused-in-childhood-fever>

of my claim that it does not work. We ought not to let an anarchy of novel, unverified or fanciful therapies be used for patients unless attempts have been made to establish either such therapies equipose with standard care, or their relative harms or efficacy as compared to current standard care.

2.7 Fallibilist health care enables ethical health care whereas dogmatic health care risks unethical practices.

In this section I have argued that health care that considers fallibilist principles of epistemology, as represented by E.B.M. processes, enables an environment of effective and ethical health care. I make the case that principles of respect for the patient, informed consent by encouraging dialogue, and striving for effective care are respected by adopting fallibilist attitudes as compared to accepting dogmatic approaches to health care that might attend less to these principles. If health care adopts a fallibilist attitude there is less room for the betrayal of patient trust and the promulgation of misguided hope⁹⁷ as might more readily occur in health care that rejects a fallibilist attitude.

Those who are guided by E.B.M. processes, acknowledge a degree of uncertainty in the beliefs that they use to make judgements, at every step of the diagnostic and therapeutic process. In using E.B.M. processes as a doctor, I seek guidance from E.B.M. based assessments of evidence and I ought to share my diagnostic impressions with the patient, go through the investigation options and discuss a breadth of treatment options (Gruner, 2000). By using such a process, the patient has the opportunity to search and seek for alternative options along the steps, and an

⁹⁷ That is, hope that is genuine, but is derived from poorly founded beliefs.

ethical practitioner needs the patient's input to care for the patient, and the patient must choose what treatments fit with their hopes. Similarly, as a doctor who attempts to adopt a fallibilist attitude, I am uncertain what will occur, so I need the patient's input as there are often very many choices to be made. Practitioners who use E.B.M, processes set up or engage in systems to merge their clinical acumen, and the patient's feelings and circumstances, with what is the latest best available evidence (David L. Sackett, 2000).

Practitioners who are seeking to be up to date and to abide by the latest evidence may be criticized by some as simply keeping up with mainstream medicine's dogma. That is; an objection might be made that to adopt the scientific method and attempt to use it in health care is to simply accept another kind of dogma - keeping up to date and following the latest middle ground consensus view is, so this objection goes, simply adopting a dogma of following "the current fashion" in health care. However, attempting to utilise "scientific dogma"- that seeks paradigm shifts- (Sackett 2000, Kuhn and Hacking 2012) is a most fluid, developing way of forming beliefs, as the scientific method constantly attempts to improve itself. Such a dogma of adopting a fallibilist attitude and attempting to give credence to beliefs based on scientific methodology, is an approach that intentionally seeks to avert dogma, and so in reality is not "dogma" at all. The processes of E.B.M. utilized by practitioners and patients who attempt to have appraisal of evidence by scientific principles (Sackett 2000) as one of the pillars I alluded to, is not just another dogma, precisely as practitioners who use it ought to adopt a fallibilist attitude and treat the current iteration of E.B.M processes on probationary. The E.B.M. process is not a form of dogma as its practitioners doubt that evidence and ways of assessing evidence will always be construed as the most credible. A practitioner using E.B.M. must "keep up to date",

precisely because what is the current trend of treatment is on probation, and it is assumed that it will likely change. The E.B.M. process is underpinned by a fallibilist attitude, in order to strive to improve systems of enquiry to find more effective care.

In dogmatic health care the patient accepts advice of the health practitioner who may be deceiving or self-deceived, and without recourse to a fallibilist attitude the patient might have fewer opportunities to choose effective care. Respect for informed consent in dogmatic health care appears to be taken by such dogmatists to be less relevant (but ethically still required), as by stepping into such a dogmatic system a patient accepts that certain beliefs are immutable and that there are not alternatives.⁹⁸ The patient may go through some processes of informed consent to come to the decision to accept a certain dogmatic health system or may make their choice based on the sorts of heuristics⁹⁹ used in choosing a friend¹⁰⁰. However, once they are in that system there is restricted scope for discourse as their illness or life views change, or as knowledge changes, if they are to remain devotees of that dogma. An example of this may be if the patient accepts health care in the context of a religious sect, then usual standards of informed consent for particular treatments might be waived by the health practitioner and patient as it is expected by the sect that the patient obeys certain social hierarchies or submits to a higher authority. As argued in my 2000 paper, (Gruner, 2000) the patient is thence more vulnerable to deception, manipulation or to the provision of futile care over effective care, if usual standards of informed consent are claimed to be unimportant. A dogmatic system of health care might limit standard

⁹⁸ A separate argument may be debated as to as to whether a patient can assert, they have a right to simply trust a doctor and wave all informed consent. There is not scope at this juncture to debate this point but it is touched on, in chapter 5.

⁹⁹ In brief, cognitive short cuts, mentioned in the context of Gert Gigernezer.

¹⁰⁰ See section 4.7

conceptions of informed consent as beliefs that challenge the dogma are rejected outright by those who subscribe to that dogma.

Indeed, a patient might share the values and beliefs of a dogmatic health practitioner and claim that they have no need for the usual information a patient might be expected to be aware of in a health care decision. The patient might claim that their dogmatically held belief leads them to absolutely no doubt about a certain decision made by the practitioner and that thus they feel no need to appraise alternative possibilities. Robert Veatch controversially claimed that we ought to abandon informed consent and that patients ought to seek out a doctor who shares their values and that this is how ethical health care choices ought to be assessed (Veatch, 1995). However what follows is an example which might suggest that making health choices on the basis of sharing a “similar culture” might lead to what many might believe to be injustice and unhealthy practice. For example, a family might live in a culture where female genital cutting (F.G.C.)¹⁰¹ of their young daughter is expected as the norm. A father or members of their culture (including some practitioners) might hold an epistemically flawed belief that such surgery is necessary to avert the daughter from bringing dishonour to the family. It seems a narrow account of informed and voluntary consent which holds that the decision that the father has made (based on a flawed belief) is an informed and voluntary choice made in the daughter’s interests simply on the grounds that he has agreed to a procedure with a practitioner who shares his values that pertain to family “protecting their honour”. Accounts of shared decision making in health care and informed consent were discussed at the inception of the field of bioethics (Beauchamp, 2011) supported by arguments that appealed to principles such as justice for the

¹⁰¹ A further account is given in footnote 110, but this cultural practice involves varying types of incisions to the female genitals.

patient, and non-maleficence to the patient. If a family (father) and practitioner believe in a dogma that directs them to believe that F.G.C is worth bringing about a child's suffering in a misguided attempt to avert any possible future extramarital sex by the daughter, it seems that the procedure is done more so for the family's honour than for the child's health.

A counter claim might be made by proponents of F.G.C that the child's psychosocial interests are best served by undergoing such a procedure, as proponents of F.G.C might claim that F.G.C is the normal practice in their culture and is what the girl must undergo to properly be part of that culture. Such claimants might suggest that not only is F.G.C necessary to avert the girl potentially bringing dishonour to the family but that the girl will suffer if she differs from most of the women of her group. However, in determining what practitioners and parents owe the child versus what the child owes the parents and her community, there needs to be consideration of the significant risks of harm that some forms of F.G.C. inflict on a child. Such risks to the child's immediate and long-term health might be considered by adopting a fallibilist attitude, whereas a dogmatic attitude might lead the child's parents to focus only on what they believe that the child owes to them; that is to "not bring them dishonour".

If parents and practitioners dogmatically hold a belief that a girl must undergo F.G.C, to maintain family honour, or to be like their older female family, then the child's voice might be ignored. By following a dogma, the child's parents might believe they ought not to listen to her pleas to avert the procedure and her parents might be led by their belief in the dogma to refuse to consider counter evidence that shows the harms of F.G.C., or to consider that they owe it to their child to not bring unnecessary harm upon her. If, however the parents allowed for the possibility that their views regarding

F.G.C might be revisable, then the daughter might have a chance to be heard and her pleas to consider some of her interests over the interests of family honour might have come into the process of the deciding on the procedure. By the parents considering the broader impacts of F.G.C on the child's health, and the possibility that F.G.C. might not avert possible future promiscuity by their daughter, the parents might re-consider, not just the adverse effects of F.G.C, but what they believe they owe to their daughter and what their daughter owes to them. By adopting a fallibilist attitude the parents might consider that their daughter does not owe it to them to submit to having her genitals altered, and that they owe it to their daughter to respect that, without F.G.C, she might not bring dishonour to the family.

The literature suggests that in the past doctors operated in a dogmatic system. In his book, *"Trusting doctors : the decline of moral authority in American medicine"* (Imber, 2008), Imber argues that in bygone times pre 1960s, western medicine saw the usually stereotypical, as I put it, "male doctor in a white coat" using mostly faith and trust as the basis of reasoning given to a patient in seeking their consent to treatment. Doctors were trained in science and were trusted as having a vocation to represent science to patients and were supposed pillars of society. Imber notes that paradoxically, as treatments became more effective, then trust in the doctor became a less pivotal reason for a patient's consent, as treatment success in many areas seemed to be independent of the individual doctor. Now with so much more knowledge and effective care in many health areas, doctors are more able to be open and to admit that their medical knowledge is limited, and that they cannot be certain of outcomes in many areas. That is, by this argument doctors have come to trade more on offering effective care based on transparent evidence of effective care, rather than more heavily relying on trust in the persona of the doctor and a supposed therapeutic effect

of the therapeutic relationship.¹⁰² Out of mutual respect, a health practitioner must accept the practitioner's fallibility, in part as the patient and practitioner are broadly speaking equally fallible. A surgeon may be less fallible at removing gallstones than a patient but must recognise that she may have "bad days", slip, or be subject to system failures like anyone else. Embracing the fact that she is fallible, as are the systems she uses, a surgeon who cares for her patients and the efficacy of what she does has opportunities to better her care and is motivated by her pursuit of best care to find and avert her mistakes and weaknesses.¹⁰³

In contrast, to adopt practitioner-centred dogmatic health care, the practitioner is setting themselves up as the focus of the doctor-patient relationship, with rights to dictate treatment to a patient. In assuming such superiority, such a practitioner risks not respecting another person's autonomy. If one group (e.g. arrogant self-superior health practitioners) believes themselves to be superior to another group (patients), then the "inferior" group might tend to have their autonomy disrespected by the superior group. The superior group might assume that they have greater "rights" or impunity from not treating their "underlings" as they would treat members of their own group¹⁰⁴. The evolution of bioethics with its principles of respect for patient autonomy and informed consent may be viewed as bringing a more egalitarian approach and shift of power from the "Doctor knows best. Trust Doctor and do what *He* says" mentality of past times. To go back to a dogmatic system of health care would seem to return to times where there was less respect for a patient's ability to make an

¹⁰² See section 4.7

¹⁰³ Such a surgeon having seen what failures lead to, is driven to avert future failures. The surgeon's awareness of fallibility is a bit like a "hoper's" awareness of despair. In an attempt to avert despair a hoper cultivates multiple hopes and works hard to attain ultimate hopes. The virtuous surgeon is ever discontent with her practice, mindful of harm and always seeks to improve and learn better ways to help patients.

¹⁰⁴ Plausibly, this mentality may have occurred in the unethical human experiments of Dr Josef Mengele at the time of the Nazi regime.

autonomous health decision, and indeed I claim a culture of less respect for patients considered “less intelligent”, “less educated” or whatever the prejudice of the time was.¹⁰⁵

As I have claimed that it is dangerous to have health practitioners setting themselves up as in some way less fallible than their patients, so too we may give credence to the idea that patient harm might come from health care systems or understandings of the natural history of disease that are infallibilist, in a way that such harm may be more readily averted in fallibilist health care systems. It seems plausible that as society changes, we develop different understandings of what represents health and departures therefrom. We even evolve what we define as health care. For example, an appreciation of the effects of psychosocial stressors on health, might not have been so great in the past, as manifested by the number of mental health practitioners now, compared to some decades ago. To be dogmatic in health care is ill founded and misguided, as what we view as disease or effective care may change in time, and unethical care might occur if a practitioner believes themselves to be superior to the patient or infallible.

2.6.2 As Clinical acumen is fallible, and practitioners owe it to patients to acknowledge this.

In my clinical experience and in teaching younger doctors, we clinicians are recurrently made humble by our expectations being remote from what eventuates. So many times, colleagues and I have advised a barrage of tests due to our levels of

¹⁰⁵ An example of such prejudice is given by Jerome Groopman where a doctor didn’t inform a woman with African American background that she had terminal cancer as the doctor thought of her as a “Salt of the earth” person who would not understand her illness and was person who would give up all hope if advised she would die.

uncertainty, or we advise a diagnostic or therapeutic path based on “clinical acumen”, and we are “shocked” when something rare or unexpected occurs. A common phrase of our medical profession in tea rooms is “rare things happen commonly”, and in practice, with more clinical experience, I am less surprised by the unexpected. In support of reason for my claim that amongst doctors there is a widely held belief that clinical surprises may eventuate, even from seeming straightforward clinical encounters, I turn my discussion now to “orphan diseases” (diseases that are less funded for research as they are so rare). Knight writes that “Rare disease is common. Estimates suggest that between 6% and 10% of the community suffer from a rare disease at any one time. This prevalence is similar to that of type 2 diabetes mellitus” (Knight & Senior, 2006, p. 82). Clinicians’ awareness that “rare things happen commonly” and that they may be missing a rare disease, or rare presentation of a common disease, is plausibly one reason that so many tests are ordered that in retrospect were “unnecessary”. I find that at times the diagnostic process is not unlike the trawling that goes on in commercial fishing, where a wide net is cast, as a clinician may reason that “it’s possible that this unexpected condition is presenting atypically in this patient”. Many times, I have advised a patient that we do a test, “just in case, even though it probably is not X”, and we make a life-threatening diagnosis. As more rare things are picked up by a clinician and patient that are potentially lethal if not caught early, clinicians are reinforced to continue advising “Trawler diagnostics”, partly because it is common for atypical presentations of serious issues. Referring to our clinic tea-room, we discuss disasters averted by “chance findings”, and we experience clinical outcomes that turn out well, despite adverse circumstances, or that go poorly with the best systems and operators. Based on such events, clinicians build up experience and might be more prone to make judgements in the context of their

training and best practice guidelines while allowing for the possibility of seemingly remote contingencies. Adopting a fallibilist attitude allows patients and clinicians to gain negative and positive serendipitous insights that they would not have realised if they allowed themselves the hubris of epistemic arrogance.

Fallible “gut feelings” may arise that lead to many diagnostic and therapeutic paths and form part of the heuristic or “system 1” thinking (that is, intuitive choices or choices made on *prima facie* appraisal) (Kahneman 2011) that are plausibly part of “clinical acumen” that forms part of clinical expertise¹⁰⁶. Such “gut feelings” may be hard and imprudent for the patient and practitioner to ignore, but in a fallibilist model of the doctor-patient relationship such feelings require further deliberation, dialogue and corroboration with external evidence, such as (also fallible) guidelines based on best available evidence. Plausibly it can be held that clinical acumen develops by working in a discipline and by gaining exposure to repeated occurrences that seem to fit certain patterns. A clinician with greater clinical acumen than another might be more adept at communication skills to comprehend the patient’s symptoms, situation, views and each other’s biases, in order to best assimilate evidence for the patient to build informed health hopes. Such a clinician also might see patterns that fit many similar past clinical situations that the clinician has seen before, or be technically skilled at a procedure, compared to a novice. However, in a fallibilist system we accept that success is uncertain, and that the evidence shows that indeed older clinicians

¹⁰⁶ An oncologist becomes an expert in one field, having cared for many men with testicular cancer, witnessing the history of such cancers before. An expert doctor has deliberated on what options a patient has, many times, with many colleagues and patients and has seen the outcomes of decisions made, positive or negative. An expert not only knows success, but failure. An expert ought to try to become aware of the common biases in their area of expertise in order to be more self-reflective and learn from past less well-founded judgements made influences from bias. The doctor may be wise in the area of testicular cancer, in the sense of having extensively studied the area and had experience in the treatments of such cancer. Such an expert doctor would have also expertise in the phenomenology of a cancer, for the patient, family and carers. The doctor’s wise choice is a choice pooled from much personal experience and deliberation with other experts and non- experts. An expertly made choice rests on (imperfect) knowledge of the success *and failures* of the past.

generally speaking might make less accurate diagnoses than their younger colleagues (Howick 2015). In addition, empirical data suggests that relying more heavily on clinical acumen, in parts of the E.B.M. system where there are clear “mechanical rules” (Howick, 2015, p. 169) of care, leads to less effective patient care (Howick et al., 2010).

Accounts of the process of E.B.M. place clinical acumen as one of the three pillars of support for E.B.M practice. The E.B.M. process attempts to merge clinical acumen with patient feelings, values and situation and the latest best available evidence for effective care (Sackett 2000(Howick, 2015). Clinical acumen is in part idiosyncratic to the clinician, and forms part of what the patient might determine is trustworthy about a practitioner; however those who are guided by E.B.M. processes ought to acknowledge that the clinician’s judgement ought to be reactive to new discoveries or serendipitous findings. The intellectual humility of fallibilism in ethical health care allows for testing of clinical acumen and the patient’s beliefs, with novel ideas.

An ethical health practitioner, as part of the informed consent discourse, owes it to the patient to inform the patient that though the path that the practitioner suggests generally attempts to use (where it is available) “best available evidence”, this path is more or less influenced by a clinician’s clinical acumen. Clinical acumen is directed by the practitioner, who in the context of the doctor-patient relationship that I will discuss, should do their best to comprehend the patient’s understanding and feelings, along with the “facts” gleaned from history, examination and tests. In my own practice, I will often flag a point of the consultation to the patient to state that the path we are heading down is more based on my clinical acumen than evidence well assessed by scientific principles, due lack of research in an area or as current evidence or guidelines that do not fit their situation. So “buyer (or in this case patient) beware”. I may cite guidelines

and studies in my dialogue with a patient, however I ought to make it clear that if the path we are going down is not middle ground consensus care, or there is not much evidence for what E.B.M. based systems support, then the patient must be informed that the evidence we are discussing is not robust. I ought to advise a patient that the choices I make as to what evidence I choose to present to discussion is subject to my biases, or to the biases of others. By being guided by processes of E.B.M., which acknowledge the importance yet fallibility of clinical acumen, the patient and I are not just protocol driven, and we allows for serendipity and an ethical trial of therapy when evidence is poor or when guidelines do not apply well to an individual patient.

Finally, I have emphasized that a practitioner or guidelines are not infallible, and that it is untruthful to intimate that they might be infallible as doctors might have done in the past. No health system, therapy or practitioner's clinical acumen have any mysterious origin that is beyond possible appraisal by the patient or those invested in the patient's wellbeing. The basis of a practitioner's advice is fallible, as are the processes that a patient uses to make health choices. Were a practitioner to intimate that their practice was anything but fallible, then not only is that practitioner being deceptive, but the practitioner fails to provide what they plausibly owe to the patient. The practitioner owes it to the patient to not deter the patient from considering effective alternatives by advertising one modality as infallible. One modality might be more appealing to a patient for many reasons, but any modality that might be attempted in health care cannot be always infallible and so the patient ought to at least have the opportunity facilitated by the practitioner to consider alternative possibilities with respect to the patient's health. If the patient adopts a fallibilist attitude, they ought to acknowledge that any therapeutic modality might fail to assist in what they hope for in their health care. The next chapter argues for a model of the practitioner and patient

relationship, whereby they can decide upon what ought to be acknowledged as a belief or value the parties ought to utilize to make health care decisions that are respectful to the patient, those who care for them and those who are impacted by the patient's health or otherwise.

Chapter 3: What patient and doctor owe each other when both approach the relationship with an attitude of fallibilism.

3.1 Introduction

In this chapter I argue that if we adopt an attitude of fallibilism, we ought to be guided by three constructs (see diagram 1) that I claim all rest on fallibilism, and naturally fit together in how they all rely upon people to at least consider one another and at times to engage in co-deliberation with one another. I highlight the associations between the three constructs, to develop a schema that may be referred to when reflecting on the ethical use of the use of hope and trust in health care, in the final chapters. Given the plurality of values and beliefs that people may hold when they enter into a professional doctor and patient relationship, both parties need to determine what they expect of each other, and what health related beliefs, values and principles ought to apply in their unique clinical situation. I argue that the schema I describe may be used by the patient and doctor to not only determine what they owe to each other if they are to continue in a respectful professional relationship, but also that they may use this schema to determine what ought to be rejected as justifiable to one another, ethically and epistemically.

3.2 How the doctor and patient ought to approach “Medical Pluralism” and not reject outright any appraisal of the process of E.B.M.

In this section I aim to demonstrate that openness to dialogue about differing ideas in medicine is what is rightfully meant by medical pluralism, and that those who properly use processes of E.B.M. embrace medical pluralism as by adopting a fallibilist attitude they remain open to appraising a plurality of ideas. “Patient centered care” as represented by “shared decision making” has been much vaunted in medical schools for decades. If this teaching is followed, it might be more likely that medical practitioners can recognize that different patients have differing beliefs, values and circumstances. In an account of this process Cathy Charles writes that,

....key characteristics of shared decision-making [are] (1) that at least two participants--physician and patient be involved; (2) that both parties share information; (3) that both parties take steps to build a consensus about the preferred treatment; and (4) that an agreement is reached on the treatment to implement (Charles, Gafni, & Whelan, 1997, p. 681)

Care can be tailored to the unique patient who is the focus of care when practitioners acknowledge that patient might have differing beliefs to the practitioner as with such recognition the practitioner and patient can begin to understand their differences. Practitioners of E.B.M. who utilize the account of pluralism that I will argue for can acknowledge that there are many health care beliefs and can work with patients to deliberate upon what is deemed well-founded or reasonable care, versus what types of health care cannot reasonably be tried or tolerated by either party.

The involvement of “medical pluralism”¹⁰⁷ in the process of E.B.M. arguably comes

¹⁰⁷ See section 3.2 for an account of medical pluralism.

from one of the original formulations of E.B.M. by David Sackett;

Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. By individual clinical expertise we mean the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice. Increased expertise is reflected...in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care (Sackett 1996, p. 71).

That is, the processes of E.B.M. recognize increased expertise as acknowledging the pluralism of patients' beliefs through "thoughtful identification" of the patient's varying circumstances, preferences, and rights.

The degree of openness seen in scientific method facilitates engagement by those who refer to it to consider new ideas and methods. In striving to have scientific evidence for effective care, those who develop and refer to E.B.M. processes endeavor to provide more effective care through scientific principles. Karl Popper described the scientific method in which scientific hypotheses can never be finally confirmed as conclusive but are tested by attempts to falsify them (Popper.K, 1934). Scientific method (that people who are guided by processes of E.B.M. may consider as one of the pillars of decision making) thrives with pluralism in the sense of pluralism referring to receptivity to considering differing ideas. This is shown by scientists peripatetically searching for new ideas to evolve and in doing so possibly refute current paradigms. As stated in the previous chapter, the processes of E.B.M. encourage

criticisms which implies acknowledgement by those who refer to scientific methods that there might be beliefs that differ from those in current E.B.M. practice. Processes of E.B.M. establish systems to check for errors and outmoded practices and in this way are embedded with medical pluralism if that pluralism is concerned with openness to deliberating upon diverse ideas.

In the previous chapter I argued that if doctor and patient adopt a fallibilist attitude, then they might also recognize that they might not always feel certain about what the outcome of their health choice might be, nor how conclusive the evidence is or that a particular belief will assist them in what they pursue. With such uncertainty, and awareness of fallibilism, the doctor and patient might be better placed to acknowledge that there might be more than one, and indeed perhaps many plausible beliefs about health care. This plurality of beliefs in health care is the basis of a notion of “medical pluralism”. I argue in this chapter that medical pluralism can more aptly be construed as an approach involving a level of receptivity to considering a wide range of ideas in health care, without necessarily accepting that such ideas ought to be used in health care as such ideas might be manifestly ill founded or unethical.

To acknowledge or respect something is not to necessarily accept it. To not necessarily accept but respect that some considerations has been undergone to form a belief in a health practice, fits the scientific methodologies relied on by those who use E.B.M. processes¹⁰⁸. Furthermore, respecting medical pluralism will not necessarily lead to a possible concern about an anarchy of health beliefs, if we provisionally utilize what is plausible and respectful to others and reject for now beliefs that are highly implausible or disrespectful to others.

¹⁰⁸ That is, in the process of science, a belief not yet well appraised should not be rejected outright without some appraisal and may be further scrutinised, as those who use science ought to recognise fallibilism of processes. What is currently not well appraised may become mainstream as more robust evidence develops in support of a belief that is not currently utilised.

Another account of medical pluralism is that it is more than a recognition that there are many approaches to health care, which would seem uncontroversial, or (as I will go onto argue against) that we ought to be “morally committed to openness”(Tilburt & Miller, 2007, p. 489). However perhaps a better account of medical pluralism would have us not committed to openness but to “receptivity of consideration”. If openness includes supporting processes of receptivity and welcoming dialogue in health care, then such openness seems (as argued below) to be acknowledged as something constructive by those who utilize processes of E.B.M. If medical pluralism means being morally committed to accepting that there are different notions of what is morally right for each person then that would seem to be adopting a relativist approach that I will argue in this chapter ought not to be done in all health care situations.

I seek to highlight the differences between several accounts of pluralism, and I will argue that in the context of ethical health care, pluralism does not mean that “anything goes”. Having argued that some conceptions of pluralism go too far, I will subsequently defend my position that reasonable tolerance leads the ethical health practitioner to not necessarily abandon a patient’s care, should the patient wish to refuse safe curative care in favor of what is plausibly regarded as poorly grounded care.

The literature on medical pluralism indicates that there are a range of views as to what its meaning is. For example, a more moderate definition is offered by, Wade who writes that, “Medical pluralism can be defined as the employment of more than one medical system or the use of both conventional and complementary and alternative medicine (C.A.M.) for health and illness”(Wade, 2008, p. 829).

Such a definition suggests that medical pluralism refers to the drawing of ideas from different sources for health care.

A more relativist approach to the meaning of medical pluralism that I argue against is the claim that,

In sum, the practice of medical pluralism will mean moving beyond any medicocentric claims for the ultimate ability of biomedicine to incorporate all C.A.M. therapies that are of use while discarding the rest. This will require suspending any categorical disbelief in C.A.M therapies...adopting skepticism about any claim that conventional biomedical research and practice exhaustively account for ...health and healing...." (Institute of Medicine (U.S.). Committee on the Use of Complementary and Alternative Medicine by the American Public., 2005) Chapter 6, Section 4.

A yet more contentious definition of medical pluralism is provided by John Tilburt who divides medical pluralism into a factual "commitment to openness" and a "moral sense" of medical pluralism when he claims that,

The moral sense of medical pluralism accepts the factual nature of multiple healing approaches and adds to that certain ethical obligations. This moral sense of medical pluralism implies that we should go beyond acknowledgment and actually act differently because there are so many potential approaches to healing....just recognizing the facts is not sufficient, but rather medical pluralism requires a moral commitment of openness. (L. Snyder, 2007, p. 209)

However, this passage could be interpreted in two ways. A "Moral commitment of openness" is not the same as a "commitment to moral openness". One interpretation by some readers might be that a claim is being made that doctors and patients owe it to each other be open to accepting that there are differing moralities in various cultures and alter their own behavior accordingly. If "behavior" refers to how we treat others in

a moral sense this can be interpreted as a form of moral relativism. However, I am not clear how far my “moral commitment of openness” ought to be in my professional role as a doctor. While I acknowledge that a good argument can be made that doctors ought to have a moral commitment to acknowledging the fact of a plurality of beliefs around matters of health care, it is a more contentious claim to make that doctors ought to accept all moral views and *a/ways* offer patients care which varies in accordance with differences between the culture or the beliefs of each patient. I argue against this suggestion of moral relativism which seems to claim that openness is a form of relativism and so is thought by its advocates to be “good”. Moral relativism might be construed as being more relevant in some domains than in others for different people. For example, one person might hold that people may have differing religious beliefs but ought to not have differing views on certain matters of sexuality. Differing cultures and individuals within cultures might have differing views on moral issues however, as this does not mean that there are not certain moral principles that seem to be held as important across all cultures.¹⁰⁹ I will later defend the claim that most forms of childhood female genital cutting (F.G.C)¹¹⁰ are widely argued to be wrong, no matter who the person is or what the cultural context is. I will defend claims that doctors might justifiably be open to the fact that the cultural practice of F.G.C occurs in parts of the world, but that doctors should not act differently towards different girls in different cultures, in refusing to perform harmful F.G.C. Those who refer to the processes of E.B.M. ought to embrace medical pluralism, if keeping open dialogue about differing

¹⁰⁹ Such as the principle to not cause gratuitous harm to others to whom respect is owed.

¹¹⁰ A practice some groups claim is in part a health practice. By using the term “most” I note that the debate about F.G.C has become more nuanced when considerations are made that *some* F.G.C is merely a ritualised nick of the genitalia that does not alter anatomy or function versus some forms that are grossly disfiguring and risky or harmful. When referring to F.G.C., I refer to ***harmful F.G.C.***, as some might argue a small genital scratch is permissible. Similarly, male circumcision has differing levels of incisions in different cultures and similar ethical consideration may arise with more disfiguring or harmful levels of male circumcision.

ideas is what comes about from an account of medical pluralism that concerns openness to receptivity of consideration of the other person's views.

3.3 Where there is lack of any level of appreciation of medical pluralism disrespect might be shown to others where respect is due.

I now turn this chapter to consider the opposite of openness to the receptivity of consideration of new ideas and consider what might manifest if people shun pluralism of any form or reject openness to appraising beliefs other than what they construe as their own. Disrespect to others might be manifested if a patient or practitioner believes that they need not accept any form of pluralism pertaining to health beliefs. Distrust based on ill-founded epistemic grounds may be a potent reason why people reject reasonable pluralism. Empirical studies inform us that one reason people use some forms of alternative or traditional medicines is out of a distrust of science and the processes E.B.M. and faith in perceived traditional or religious values. (Institute of Medicine (U.S.). Committee on the Use of Complementary and Alternative Medicine by the American Public., 2005; A. Simpson & Rios, 2019). For instance, a person who has a dogmatically held belief that they will only accept health care if it is what they consider to be “natural” or “free of chemicals” might miss out on opportunities for continued health if they are not able to avail themselves to the benefits of medical pluralism, as defined as examining many modalities and being open to at least appraising other ideas.

On the other hand, there rightfully may be critique of practitioners guided by processes of E.B.M. who prematurely reject a traditional medicine or alternative health practice and disparage it outright without attempting to understand it. To do so is to

reject pluralism as a means of at least being receptive to considering differing ideas. Authors in one publication claim that the commitment to openness required to fit the account of medical pluralism that they subscribe to requires “suspension of a categorical disbelief in C.A.M” by those guided by “usual scientific norms”(Institute of Medicine (U.S.). Committee on the Use of Complementary and Alternative Medicine by the American Public., 2005, p. 171). While this may be true of some doctors, it is not the case for all, as evidenced by one reading of Sackett's definitions of E.B.M.¹¹¹ (whereby doctors need to understand as well as they can and account for patients' circumstances, beliefs and feelings) and by the existence of medical colleges of “integrative medicine” such as the Australian Medical Acupuncture Society. Similarly, while most patients may accept the need for chemotherapy for testicular cancer, some might reject out of hand any suggestion of such curative care, as they may say that they “hate chemicals and don't trust doctors”. However, principles of mutual respect and some form of trust are needed to facilitate the pluralist dialogue. Such dialogue seems integral to the model of the ideal doctor-patient relationship I outline in the next section, whereby in a relationship where both doctor and patient agree to respect each other they acknowledge that they will come to the relationship with differing beliefs and values and that in cases of disagreement they ought to discuss such values and beliefs as relevant to the patient's health care. More broadly, in order to have a dialogue, one must be receptive to another's ideas or beliefs. Michael Slote (Slote, 2013) discusses receptivity as an essential element of caring, whereby a health practitioner is attending to and conveying to a patient the feeling that the patient is being carefully listened to. That is, part of care is showing respect by being receptive to the patient's “ideas

¹¹¹ See section 2.4.1.

concerns, expectations”¹¹² and feelings.

Assuredly, there may be virtue in such receptivity and Slote argues that receptivity is important in both patients and in doctors, as receptivity might be impaired if a patient refuses to listen to a health practitioner's view. To provide an illustrative example, I now move onto a fictional composite case that may be illustrative of some alternative medicine groups, such as some members of the Church of Scientology (Kent S.A, 2014; Larkina, 1999). In such groups there may be not only a resistance to standard health care, but a feeling of being at war with those who are part of the process of E.B.M. or its proponents. For example, a 25-year-old with testicular cancer (that could be readily cured by relatively safe short term chemotherapy) who “hates chemicals and the medico-industrial complex” might adopt a partisan approach that places him within a particular “moral tribe” (Greene, 2013). The reader might recall that members of a moral tribe might believe those in their tribe to be morally right and those outside their tribe to be morally wrong. Furthermore, they might believe members of their tribe to be worthy of respect and those outside their tribe to be unworthy of respect. It may be that part of the 25-year old's sense of personal identity¹¹³ is derived from being part of that tribe. The tribe and the 25-year-old who identifies with it might dislike the pharmaceutical industry along with doctors who the 25-year-old regards as being supported by the industry. In this fictitious 25-year old's case, we consider where a person has an emotional attachment, to a rejection of science (Furman, 2020) more

¹¹² As is often discussed in communication skills training for doctors. (Morgan, Chan, & Starling, 2014, p. 646)

¹¹³ I mention the concept of identity several times in this thesis. Identity may consist of many features but part of what forms a person's sense of identity might include awareness of self as a continuum over time, sense of belonging to a group such as a culture, race, nation or religion (Appiah, 2016). Perhaps most importantly a relational aspect of identity- that is, who that person is important to, and who is important to that person and what they believe they owe to each other is an important part of any account of identity that is used in discussion about ethics.

broadly and more specifically to chemotherapy. Along with a dislike of chemicals, there might be a distrust of all doctors who they perceive to be part of a huge process of E.B.M. that they feel alienated from.

However, even if interpersonal distrust is present, this need not preclude a dialogue or a level of mutual respect between a health practitioner and a patient. An awareness of what emotionally influences them to interpret evidence in differing ways might assist a doctor and patient to acknowledge the possibility of adding a plurality of beliefs to what they consider that they ought to deliberate upon. Returning again to Michael Slote (Slote, 2013), he posits that to fairly evaluate an argument we need to view it while self-consciously aware of our emotional attitude to the argument. By Slote's view we ought not to believe that we may be what I will term "dispassionate reason machines", as an extreme version of Kantian rationalist philosophy may suggest. If a person holds a bias¹¹⁴ that provides ill-grounded feelings of anger or hatred¹¹⁵ towards another person or group, that person may reject evidence that challenges or refutes a position that they hold and may seek out and amplify the value of evidence that supports the position that they have already adopted. Furthermore, with "confirmation bias", people tend to more readily accept evidence that supports their current beliefs and tend to reject evidence that contradicts held beliefs. A fallibilist view portrays doctors and patients as uncertain about whether they come to rational deliberation without emotional influences. Indeed, journals that are part of the process of E.B.M. provide us empirical data on the common biases doctors have and on how to counter such bias (Blumenthal-Barby & Krieger, 2015; I. Scott et al., 2017). In such a setting of uncertainty as to how much emotions may influence what we come to believe, doctors

¹¹⁴ Bias is given more extensive discussion in section 4.8.

¹¹⁵ And so are less dispassionate.

and patients need to be on guard lest emotions or feelings such as greed, anger or hate, bias us away from the patients' best interests in how we make health care choices. We might be aware that we might feel antipathetic toward a type of person who is attempting to debate our beliefs. Awareness that hostile emotions may bias us to reject what a person we dislike offers as evidence and may help us to assess possibly well- founded new data or even moderate our hostile emotion when we reflect on its causes and effects. We all are imprudent if we limit information that we may have available to us in high stakes health choices and to "cut off" new information just because it comes from a person who we dislike. Accepting that we are all fallible, we ought to accept that the person who we dislike has come to hold a perspective for certain reasons. Whether the person is liked or disliked, it is not implausible that we may gain from seeking to understand how they developed the ideas they have. Slote builds on accounts that there are epistemic ideals of objectivity, that is, of being fair and open minded, even to those we dislike. He rightly argues that there is merit in being receptive to another's arguments and attempting to see them in a favorable light in order to understand them. Having discussed a few understandings of the nature of medical pluralism and some of the possible consequences of tolerating unreasonable beliefs versus the consequences of rejecting outright all beliefs except for the one that we presently hold, I now return to a discussion that argues for ways to decide how doctor and patient might determine what may be not reasonably tolerated in health care and what they ought to do about it. It is important to my thesis that medical pluralism is not to be conflated with moral relativism. I will discuss in section 3.8 the nature of tolerance and its limits. It is an error to believe that pluralism involves accepting all ideas and behaviors as being well-founded and or acceptable. In support of this claim Isiah Berlin wrote that,

...for all human beings must have some common values or they cease to be human, and also some different values else they cease to differ, as in fact they do...That is why pluralism is not relativism -- the multiple values are objective....if I pursue one set of values I may detest another, and may think it is damaging to the only form of life that I am able to live or tolerate, for myself and others; in which case I may attack it...(Berlin, 1998, p. 16)

That is, for Berlin, we all hold some values in common as this in part defines us as human, however some values we ought not share and indeed ought not tolerate. Such an account seems on *prima facie* appraisal to be plausible to hold as indeed there are some values that we all share, such as for example the value of having a degree of at least some form of respect from others or to have a level of self-respect. Despite such a possible “common value” amongst sentient humans¹¹⁶ it seems plausible to believe that we do not, and ought not to all share the same values with respect to a wide range of issues. Additionally, Berlin lends support to the argument of the previous paragraphs that we have the ability to understand those we dislike in order to promote mutual understanding when he comments that,

...if a man pursues one of these values, I, who do not, am able to understand why he pursues it or what it would be like, in his circumstances, for me to be induced to pursue it. Hence the possibility of human understanding....”(Berlin, 1998, p. 27).

With some understanding of others’ values, there is at least the possibility of respect for others and consideration of a level of pluralism.

Pluralism of values need not lead to an anarchy of deliberations of agents, or to relativism, as a tolerant harmonious society ought to develop ways of weighting which

¹¹⁶ There are possible exceptions where people are for example, incapable or incapacitated.

values may apply in various cases by processes of respectful mutual understanding and dialogue. I go onto argue that such processes can apply to health care in coming to determine what beliefs may be reasonably tolerated by patient and doctors in each clinical setting. For example, “Dialogical consensus” (Parekh, 1996) is a process whereby a society debates the relative importance of various values in determining what is “right” in a contentious area. Further examples of how societies determine what level of pluralism of values is reasonable come from Tristram Engelhardt who refers to “moral friends” (Engelhardt, 1986) and Joshua Greene who writes about “moral tribes” (Greene, 2013, p. 27). Engelhardt conceives of our “postmodern society” as including so many individuals that inevitably most individuals have a differing moral view to their neighbors. “Moral friends” share similar moral intuitions and refer to the same moral authority or moral precepts for guidance over a point of moral debate. “Moral strangers” may not agree with certain moral authorities or may hold differing values of what it is to lead a good life. Moral strangers differ amongst themselves about which principle is best applied in certain moral dilemmas. In the models of Parekh, Greene and Engelhard, groups of people choose to co-operate together despite possibly conflicting (or varied interpretation of the importance of certain) values by coming to agreement through discussion and co-deliberation. These models may be applied to the doctor-patient relationship.

3.4 Emanuel and Emanuel; A model of the doctor-patient relationship that might be referred to in order to facilitate respectful dialogue between doctor and patient in a setting of medical pluralism.

The last few paragraphs have discussed values and pluralism and I now wish to

move towards the subject of how a doctor and patient may determine the boundaries of their relationship with one another. By boundaries I mean what either person agrees they cannot reasonably¹¹⁷ reject as something that the one owes to the other. For example, a doctor and patient might agree that they cannot reasonably reject that they ought to seriously listen to one another's' opinions in cases where the other might feel disrespected if not attended to by other, when they feel that they ought to be heard. In the cases of major disagreements that I focus on, I seek to discuss what principles a patient and doctor may determine that they cannot reject as being important in guiding them about what they define is reasonable, amongst the plurality of possible beliefs about the nature of their relationship. By reason, I am not referring to reason in the sense of logic, but to what either party cannot reasonably reject as fair and considerate to one another. In turn I use the word fair, to refer to what either party has determined is a normative expectation of the other that they both cannot reasonably reject if they wish to maintain a good respectful relationship. In discussing what principles, the doctor and patient determine that they cannot reasonably reject I will draw from the work of Emanuel and Emanuel (Emanuel & Emanuel, 1992) and Scanlon (Scanlon.T 1998).

Values are plausibly understood as the underpinnings - based on beliefs - of principles; and principles are used to guide people who may have differing beliefs but want to live or work in some way together. In broad terms, some moral points of debate may be more peacefully resolved through co-deliberation about the principles that determine what is "not wrong" for a patient, their practitioner, and their broader society. We may concede that it is difficult to debate another person's beliefs or values, but we may work with members of a group who share a goal to determine what principles they

¹¹⁷ See section 3.6 for a discussion of "reasonable".

may agree to (or not reject) in order to achieve a goal such as economic cooperation, peaceful co-existence, or understandings of each other's beliefs in health care. Even with better understanding of another person's position we may not find that we cannot reject the others position. Alternatively, we may avert potential conflict and choose not to maintain anything but a remote relationship with a person who we disagree with and not even bother to debate a moral issue with someone. However, such a remote relationship would seem not to characterize what might be a common expectation of the doctor-patient relationship where the patient comes to the doctor for some level of health care. In the ideal doctor-patient relationship, we may rightfully expect that each individual ought to act in certain ways towards one another and consider the interests of the other in a manner that is not usually expected from someone who is remote from them. Such a relationship is in a sense special, and I will refer to it as "moral relationship" where two people have some clear obligations to one another due the nature of their relationship (e.g., the doctor-patient), as compared to a remote relationship where one person might be at the opposite side of the globe and be unaware of the other's existence¹¹⁸.

A discussion of what principles may best apply is found in the I.D.D.P.R. The doctor is regarded as not just a person who bestows, cures, or gives a patient data, but as someone who engages in dialogue with a patient. In Emanuel and Emanuel's "deliberative" model, the doctor is in part analogous to a friend or mentor, in that the doctor works with the patient and acts in their interests and guides the patient on matters pertaining to health. The doctor's professional role involves not only advising on health knowledge, but also in helping a patient to determine what principles more

¹¹⁸ I may have a type of relationship with another member of my football team who live interstate whom I have not met as I feel an affinity for "X" supporters as they share certain values with me. I also may feel an affinity or feel a sense of relationship with those from my "moral tribe" as outline in chapter one and section 5.9.

aply apply in certain health situations.¹¹⁹ In the example given by Emanuel and Emanuel, the doctor rightfully advised a woman with breast cancer to enroll in a chemotherapy trial, as by enrolling in the trial, the women with breast cancer would get best available care and in addition the doctor appealed to the principle of altruism in helping others. Rather than give advice that “In my medical opinion you should have chemotherapy” or simply present the facts and let the patient choose, the doctor’s role was to have discussions and advise the patient, based on what the patient presented as their values and beliefs, and on what principles may best be applied in reaching an important health care decision. Deliberation is required of the doctor in knowing the patient in their context and what their preferences are in the setting of the health issue. In keeping with a model of shared decision making in health care, the patient deliberates on choosing with the doctor, what health issues to discuss, and what advice to accept or reject.

A critique has been given that the ideal deliberative approach might not be “ideal” from the point of view of some patients. Devereux writes that some of her patients that said, “You’re the doctor. I will do what you tell me to do.” (Devereux, 1992, p. 1410). My own patients have said similar things to me many times, for example when I attempt to discuss the pros and cons of prostate cancer screening with a man who has been told to come in for a “check- up”. So, the criticism may be made that though ideally patients ought to arrive at substantial understanding and co-deliberate with their doctor on shared decision making, this is not what occurs in most clinical settings.

¹¹⁹ From the literature on “epistemic paternalism” (Goldeberg, 1991) in the manner that a judge may determine what is a jury’s “requirement of total evidence” (for justice to be done), so perhaps doctors may be argued to have a duty to persuade a patient to look at what is generally considered salient evidence and not reject evidence due to biases beliefs or values worthy of consideration. The patient still chooses what to believe, so is not coerced, but is invited to consider what “communication controllers” deem as “requirement of total evidence”. In the health field, “communication controller” is too harsh a conception of a doctor’s role as described in the ideal deliberative care model of Emanuel and Emanuel (Emanuel EJ, 1992), however epistemic paternalism may be referred to as a possible justificatory reason as to why doctors seek to ensure substantial understanding.

However, such a broad claim requires empirical support, and in any case the aspect of the I.D.D.P.R. is a guide to, rather than a description of the doctor-patient relationship. Emanuel and Emanuel responded to this concern by saying that the ideal deliberative model allows for doctor and patient to determine what values might apply in each setting, including at times prioritising paternalism. The I.D.D.P.R model allows that some patients may at times value respect of an expert's opinion over any need for them to apply their usual cognitive processes of appraisal to a health decision. A doctor and patient may deliberate, or they may instead just rapidly agree to the doctor having such responsibility in some settings, such as the acute care required for a patient having a heart attack. The I.D.D.P.R facilitates those who are involved in it, as does the ideal processes of E.B.M, to consider that that each clinical case is unique. While co-deliberation and "shared decision making" might be ideal in for example a long-term doctor-patient relationship, the ideal might not be possible to attain in many cases. In that way the I.D.D.P.R and "shared decision making" can be viewed as models or processes to refer to, especially in cases of disagreement between doctor and patient about major health decisions and what either owe to the other.

3.5 The I.D.D.P.R., the process of E.B.M and Scanlon's "What we owe each other".

The system of ethical enquiry of contractualism rests on notions of deliberation between two people as do many aspects of the model of the I.D.D.P.R. I highlight that there is also an association between Scanlon's work and the ideal process of E.B.M.

in that both constructs are not prescriptive in defining what is “right or wrong” but rather both constructs may be used to guide individuals in determining what they ought *not* to decide upon if they are to avoid ignoring how they impact certain others. A third association I make in this thesis is that the process of E.B.M. *also* relies upon co-deliberation between individuals in their unique clinical setting who in turn often rely on the co-deliberation of many others.

It is striking to me that there are not publications in the bioethics literature on the association between the three above constructs relying upon the belief that a level of co-deliberation can be used in determining how the doctor and patient ought to consider others. I believe I am offering a novel link between aspects¹²⁰ of Emanuel and Emanuel’s account of the I.D.D.P.R., Scanlon’s work on contractualism and the process of E.B.M. The three idealized constructs are interlinked and may be referred to by a doctor and a patient in determining what their special professional therapeutic relationship ought to be by determining what it ought not to be, particularly in a world with a plurality of values.

Scanlon’s 1998 book “What we owe each other” in which he developed a type of contractualism, Emanuel and Emanuel’s 1992 article and Sackett’s 1996 paper were published at around a similar time. Contractualism is not a stand-alone ethical system that directs people to, for example maximize a notion of the good. Rather contractualism may be used by people who have a relationship to determine how they

¹²⁰ By saying “aspects”, I mean to say that I do not claim that the entirety of the Scanlon, Emanuel and Emanuel’s work and every fact of the process of E.B.M. may be referred to by a patient and a doctor in a difficult clinical encounter where they seek to determine how they ought to engage in their relationship. The aspects seen in all three constructs that I wish to refer to include; the need for mutual respect in the form of consideration for the other, fidelity to the co-deliberative process that follows from mutual respect and both parties recognising the importance of shared decision making while being open to appraising evidence from what they determine are credible sources.

ought to (not) relate to each other while being sensitive to what they both may not tolerate. Specifically, contractualism assists people to determine together what ethical principles they ought to refer to in agreeing to what they owe each other.

Thomas Scanlon (1998) argues for a contractualist account of ethics whereby agents accept that to coexist in an environment, a level of mutual respect is required, whereby principles they apply to others, equally apply to them. A moral act is one that we can justify to others, having applied principles in a way (that I will soon discuss) that others cannot reasonably reject in being responsive to others' concerns. I here quote from Thomas Nagel who writes of Scanlon's work that,

The idea is that if our aim is to be able to justify our conduct to others, we will want it to conform to principles that none of them could reasonably reject, because then everyone who shares our interest in justification would in effect be prepared to license what we do insofar as it accords with those principles. If we deliberately do something that is in this sense wrong, we are in effect saying we don't care about its admissibility to reasonable others. (Nagel, 1999, p. 3)

Central to this account of contractualism is the acknowledgement that people appraise their position with consideration to those that they may need to justify their position to and that they remain aware how they might affect others and what others might think of them¹²¹. An act may be wrong not just because some normative code is violated but because the perpetrator of the act is flouting a code that on closer inspection is there for reasons of considering the interests of others and respectfully attending to their concerns. This is particularly relevant in the doctor-patient relationship where, as I will

¹²¹ Social science research suggests that part of being human is to have a "theory on mind", whereby people make up representations of how other people think and feel and react accordingly to those representations of people. Michael Tomasello and others claim that humans co-operate in ways unique from other animals and collectively attend to matters of, for example, the values of others by "checking in" with those around them (Tomasello & Herrmann, 2010) .

discuss in the chapters on hope and trust, what is considered to be wrong about an act might not just be the breaking of a normative code, but the lack of consideration shown to the other.

If we consider the so-called golden rule, “Do unto other as you would have them do unto you”, we might reverse the rule to be closer to Scanlon’s account to say, “Do not do unto others as you would not have them do unto you”. In both cases one person is directed by the rule to “put yourself in the shoes of others”, consider what the other is feeling or thinking and have a “theory of mind”(Premack & Woodruff, 1978) of the other. The construal that one ought to consider the other and not act in an “atomist way”¹²² lends itself to what a doctor and patient might plausibly expect of their ideal relationship, whereby the doctor ought to account for the patients’ feelings and circumstances (as ideally guided by the process of E.B.M) and the patient ought to attend to the doctor as that is why they came to the doctor. On Scanlon’s account we may not disregard the standpoint of the others with whom we have a relationship (if their principles cannot be reasonably rejected) as to do so may lead to them to disregard our standpoint. The principles that we apply to them, if not rejectable on reasonable grounds, may equally be applicable to ourselves. As Scanlon notes,

“An act is wrong if its performance under the circumstances would be disallowed by any set of principles for the general regulation of behavior that no one could reasonably reject as the basis for informed, unforced general agreement...”(Scanlon.T, 1998, p. 153).

Pluralist ideas and values may exist in a society, but mutual respect requires forming agreements as to what principles ought to *not* to apply in particular circumstances to

¹²² As discussed in section 3.1.

decide which person's values ought to be prioritized or not tolerated. Scanlon's example, is of Jones, who is pinned down under electrical equipment that is transmitting the live world cup coverage, and is in great pain that can be immediately stopped by a maneuver that will kill Smith, also pinned down (Scanlon.T, 1998, p. 235). We may reasonably reject an appeal by Jones for immediate relief at Smith's expense. This is because we may reasonably reject Jones's pleas for immediate relief as to do so causes greater harm to Smith, and Jones cannot reasonably reject that people in a society would not want their lives sacrificed for the temporary discomfort of others. If however Jones's pleas for help meant that immediate relief for him would delay millions of viewers their T.V watching for 15 minutes, it seems that we cannot reasonably reject the idea that averting agony for one person, takes precedence over inconveniencing millions or people. We cannot reasonably reject the principle that bringing minor inconvenience to many is worth it to avert great harm to one person.

In a further example of what he means by what ought not to be tolerated Scanlon writes that,

"The fact that it would be slightly inconvenient for me to keep a promise should be excluded as a reason for doing so"(Scanlon.T, 1998, p. 156).

In both this example and the example of Jones and Smith Scanlon seems to be arguing that certain sorts of behaviors ought to be ruled out. In this manner Scanlon's process does not support an extreme form of relativism as it does set boundaries on what ought to occur between people. The process that Scanlon describes is not meant to be fully prescriptive in all details but is to be used for people as a guide to determine what principles might be best applied in their unique circumstances, and I will go into how what people determine that they cannot reasonably reject pertains to matters of mutual respect and minimal level of consideration of others to whom that their respect

is due. Scanlon's original formulation of contractualism did not aim to be fully prescriptive, in the manner that virtue ethics, normative or consequentialist theories are used to direct people to what is "right or wrong". Rather, Scanlon's contractualism was to be used as a guide for people to work out between them which ethical perspective and considerations might best apply to their situation. As the process of E.B.M. is not fully prescriptive but can helpfully be referred to as a guide by doctor and patient, so too Scanlon's contractualism only highlights to us what should motivate us to form moral judgements.

The above-mentioned case study may be framed in a contractualist manner as an example of disregarding someone who is attempting dissuasion based on principles that can't reasonably be rejected. For example, suppose that when the doctor informs her 25-year-old patient that he has testicular cancer, the patient then refuses effective chemotherapy as he will not accept any chemical therapy. If the patient and doctor have agreed to use contractualism to determine what principles ought to apply in cases of disagreement about health care decisions, the doctor may reasonably ask the patient why he will not have chemicals and may appeal to (not reasonably rejected) principles that they have determined ought to apply in cases of disagreement within the relationship. Though Scanlon did not specifically write on bioethical principles, other authors have argued that one attraction of contractualism is its ability to take into account many principles. As Ashford claims,

"An advantage of contractualism is that it can capture the wide range of considerations that are relevant to moral deliberation. All the considerations that provide individuals with reasonable grounds for objecting to a proposed principle are relevant" (Ashford, 2018).

The patient may understand that the doctor feels a duty of beneficence to the patient

as the doctor demonstrates respect by greatly valuing the patient's life, health and wellbeing. Such a principle as beneficence may be debated by the patient and the doctor as a consideration versus the principles of patient autonomy as might be construed as supported by the patient's freedom to make even self-harmful choices.

The 25-year-old patient may reasonably be expected to consider what the doctor is thinking and feeling here. Fidelity to the doctor-patient relationship may be cited as a reason why the doctor asks the patient to listen to her arguments to and understand why she attempt dissuasion as the doctor will endeavor to understand the patients' reasons to hate chemicals and refuse treatment. The doctor may argue that the length and depth of professional relationship that may have grown over years, is a consideration that before refusing dialogue outright, the patient should reflect upon due to a principle of mutual respect. In such relationships either party may not reasonably reject that they ought to attempt to understand the other's point of view. The principles of beneficence, compassion and fidelity to the doctor-patient relationship are examples of principles that a modern pluralistic society may expect a doctor to act by. A doctor may reasonably expect that a patient will not refuse to accept that the doctor feels bound to consider such reasons for why the doctor feels obliged to attempt dissuasion of the 25 year old.¹²³ A duty to care forms part of the normative moral expectation of a doctor to be beneficent. Additionally, "Duty of care" is not only a moral professional requirement but is a normative duty in a medico legal sense. Also, by attending a doctor, a patient ought to acknowledge that the doctor has a duty to care for them and thus at least ought to consider the doctor's position in case where the patient seeks or rejects care that the doctor advises them is harmful. By next

¹²³ These principle are broader than Scanlon argued for, but fit more the "broad range of considerations" (Ashford, 2018).

applying aspects of work of Scanlon and Emanuel and Emanuel, I am building an argument that by a patient and doctor coming together in an agreed model of the doctor-patient relationship, while the doctor certainly has duties to the patient, the patient can plausibly be held to have duties to the doctor.

The deliberative model of the doctor-patient relationship establishes the doctor in a role which is, in important ways akin to those of a teacher and a friend, for example, engaging the patient in dialogue on what course of action would be best. Not only does the physician indicate what the patient could do, but, knowing the patient and wishing what is best, the physician indicates what the patient ought to do, what decision regarding medical therapy would be admirable (Emanuel & Emanuel, 1992, p. 2224).

Emanuel and Emanuel's model of the I.D.D.P.R. suggests that the doctor ought to attempt to influence a patients' values as relevant to health care. Such a model includes the important virtue of compassion that Sackett used in his definition of E.B.M. that would see a doctor as inappropriately detached if they simply acted as an "information giver" and made no attempt to dissuade a patient from futile therapy in a high- stakes health choice, such as in the case of the 25 -year- old, above. Though Emanuel and Emanuel's model might be thought to raise some concerns about being on one level paternalistic, in that the practitioner may seek to guide a patient values "for the patients good", such "paternalism" can also be more accurately construed as being guidance, and it is not immediately clear why the discussion of values is a matter that doctor and patient ought not to engage in and is paternalistic. Plausibly the doctor often has more expertise than the patient in the matter of health care and the doctor can envisage potential issues related to values that the patient has not yet imagined.

The doctor may point to the tragedy for the patient's family and for the world of losing such a unique person with special attributes due to what the doctor and broader

society perceive as epistemic errors or biases (be they epistemic, ontological or moral or cultural) that the patient has not fully appreciated. In the high stakes situation of a doctor about to see their patient embark on an avertable path to death or great suffering, the patient ought to not blame the doctor for trying to dissuade them if the patient accepts that the doctor has respect for them as a person. The doctor may justify her conduct to the patient if the patient accepts the principle that ethical health care embraces fallibilism and thus that we all may be open to biases involving epistemic errors, and that we all ¹²⁴ ought to be open to appraising such biases. The doctor would appeal to the 25-year-old patient that he may not reasonably reject that she expects he would value her (the doctor's) life and attempt to dissuade her if she were making a fatal choice due to an epistemic error or due to unappraised moral or cultural biases. Mutual respect serves as another basis for "co-deliberation" in that both parties cannot reasonably reject that they respect the importance of each other's lives. It is plausible to believe that to unreasonably reject this reciprocity of mutual respect, may make peaceful co-operation less feasible.

For instance, if the doctor were ill and required the care and expertise of the 25-year-old, should the doctor admit that she was fearful of needles or having any surgery¹²⁵ she would expect the 25-year-old to have shown her that such fear was possibly a bias, that was influencing her choice to avert effective care. It is plausible to think that the fear of pain, from being "opened up", or of needles, may be assisted and curtailed in high stakes health care choices, and that patients may justifiably expect health practitioners to point out to them such biases as this fear, and to assist them in

¹²⁴ Possible exceptions are those not sentient or incapacitated etc.

acquiring “substantial understanding” that is in their best long term autonomous interests.¹²⁶

Though it might be generally held that an ethical health practitioner ought not to use duress to dissuade a patient from a lethal path that they have autonomously decided upon, if a patient accepts a contractualist view of morality, I wish to demonstrate that the patient ought to listen to the health practitioner if the practitioner seeks further dialogue with a patient in this circumstance. In a contractualist framework, the patient cannot reasonably reject that informed consent is something that health practitioners should generally seek to encourage. Informed consent is well recognized as a principle that we expect health practitioners to strive for and substantial understanding forms a key part of standard accounts of informed consent. A doctor might express to a patient that the doctor believes that the patient has not fully appreciated alternatives to a lethal path. A patient may not reasonably reject that a health practitioner will attempt to see that the patient achieves a degree of substantial understanding with the patient’s permission as the doctor feels a duty to do so. A patient may appreciate that the doctor-patient relationship is of personal importance to both the patient and the doctor. In this manner the patient owes it to the doctor to not reject outright offers of dialogue. The patient may reasonably expect that the doctor is highly motivated to care for the patients’ health interest and that the doctor feels a personal obligation to do a good job. A “good job” of patient care for an E.B.M. doctor is to do their best to understand their patient’s situation, feelings and beliefs, in part to show care and in part in order

¹²⁶ If we accept that there are treatments for anxiety and that doctors ought to treat anxiety where it is significantly harmful to a person, we may justifiably infer that doctors in such circumstances ought to attempt to treat fear of needles, being operated on and of hospitals. Such fear is a form of anxiety that like any other anxiety may seriously impair patient autonomy for several reasons but in this context, fear may impair attaining substantial understanding. Without duress or deception doctors ought to try to treat such anxiety or point out to a patient if they are discounting relevant evidence due to emotional or cultural bias, as a means of dissuading a patient from catastrophe.

to ensure that the patient understands the relevant evidence, or possible confounding biases to decide for the patient's best health care.

A patient may counter that they appreciate the doctors' concerns, or the doctor's strong sense of duty to uphold various bioethical principles, but a patient might suggest that in a pluralist society (a) there are many types of health care ideas, and so why not accept their choice, or (b) that pluralism is a form of relativism — which is a position that I contest. If medical pluralism means acknowledging that there are many conceptions of health and care, then we need direction as to what is reasonable within the spectrum of such ideas. I now move to discuss what the term reasonable might mean, particularly as the word is so critical to Scanlon, the process of E.B.M. and how a doctor and patient may co-deliberate over values and what they determine is best patient care.

3.6 Reasonable pluralism, and the difficulty in the patient and doctor determining what they can “reasonably reject” in determining what they owe to each other.

“Reasonable pluralism” is an important notion to be explored in the context of determining the nature of the doctor-patient relationship. Reasonable pluralism was described by Rawls (Rawls. J 1993, page 101) in the setting of political arrangements that “reasonable citizens” come to. The assumption is that people who want to live together will arrive at mutually agreed terms that everyone finds acceptable. In the famous letter of John Locke on tolerance, he argues that in recognizing that a plurality of values might be held by others, individuals may sacrifice some interests to obey the common laws they agree to for a stable society (Locke & Tully, 1983). Scanlon includes reasonableness in his theory of how individuals determine what they owe

each other and is focused not on relationship of individuals with society but on the relationship between two people that I extrapolate to special profession relationship of the doctor-patient relationship. Scanlon is focused on how individuals view each-other.

As Nagel says on Scanlon,

“The reasonableness of an individual’s rejection of a principle depends on his taking the points of view of other individuals into account, but it does not depend on conformity to the verdict of an external point of view which is not that of any individual. The same applies when we are evaluating moral principles in advance. We have to imagine their prospective impact on the lives of individuals, and if a proposed principle would generate reasonable individual complaints more severe than the alternatives, it is to be rejected” (Nagel, 2002 p 150).

From this quote I take it that Scanlon’s version of contractualism postulates that what is reasonable is based upon certain more general societal normative codes of morality that may or may not apply depending on their impact on individuals and depending on what they both agree they cannot reject. In this way the problem of aggregation may be accounted for by co-deliberators where (as in some versions of utilitarian ethical theory) the good of “the many” aggregates to justify harm to the individual. The individual may be harmed as their concerns are not heard, or their interests are sacrificed for the interest of some aggregated value. In this manner they are shown a level of disrespect by the co-deliberators. Personal relationships also might be shown less value in favor of some other aggregate value. It is not my intention to discuss the literature on aggregation, but Hirose said that,

“interpersonal aggregation is the combination of different people’s morally relevant factors (i.e. good, well-being, happiness, pleasure, desire-satisfaction, claims, reasons, and so on) into a real value that represents the relation of sets of morally

relevant factors.” (Hirose, 2015, p. 5). One of the motivations to avert interpersonal aggregation might be to reduce,

“moral outweighing of one of our lives by others so as to lead to a greater overall social good”(Nozick, 1974, p. 33).

The literature on aggregation is extensive and Scanlon’s work is helpful for me in my focus on interpersonal doctor-patient relationships rather than the broad society both live in. In the I.D.D.P.R it cannot be reasonably rejected that, while this relationship exists in a wider social context, the one-to-one relationship of the patient and their doctor has primary importance. Scanlon’s work is particularly relevant in my role as a clinician in determining how I ought to respond to the individual patient in front of me, whose beliefs about a matter of health fundamentally differ from mine and we seek to maintain a good doctor-patient relationship. Scanlon’s contracualism attempts to hold as central to ethical conduct the value of the interpersonal relationship and what each individual person owes to the other. However, though Scanlon’s work may on one level avert some problems of aggregation in the doctor-patient relationship, in the literature further possible issues arise with Scanlon’s accounts.

Writers after Scanlon have written extensively on several problems with Scanlon’s contracualism. I have touched on some of these problems and will briefly mention them at this juncture then move to the important problem of what is “*reasonable*” in Scanlon’s construct.

In a similar manner that it might be objected that Emanuel and Emanuel’s I.D.D.P.R. model is too idealized and does not reflect the reality of the doctor-patient relationship, Scanlon’s model might be critiqued for being too cognitive and not reflective of the claimed intuitive nature of some aspects of morality. For example, a highly cognitive account of morality, that is determined by what cannot be reasonably rejected might

not account for our feeling of disgust at some egregious act. However, in E.B.M and the I.D.D.P.R., what is believed to be “reasonable” may not be based on purely cognitive but also on more affective measures. As I will discuss, reasonable does not have to mean rational and pertaining to norms of logic but may have a minimalist meaning that pertains to what is fair, or what people can come to tolerate.

Onora O’Neill critiqued Scanlon’s account as having no currency in cases where people do not have a commonality of goals or shared values, as might occur in cases of disagreement over values in a pluralist society. O’Neill claims that,

“Scanlon’s contractualist justifications will fail when motivation is not shared..... The scope of his ethical reasoning will therefore be limited by the fact that it does not offer reasons to those who don’t happen to share that motivation.” (O’Neill, 2003, p. 325)

Indeed, if two people have no relationship at all with each-other there might be no need to determine what might reasonably be rejected between them as they will never co-deliberate with one another, as they are not even aware of each other. A person in Melbourne may plausibly be claimed to have a moral relationship with a person in a refugee camp in Syria, however such an example is not a professional relationship like that between the doctor and the patient. In coming together as a doctor and patient it is reasonable to claim that both parties have some commonality of goals and shared values, for example to aid the patient’s health in some way and to behave towards the other in certain ways. After all, the doctor reasonably is expected to have a goal in common with the patient of helping the patient’s health and the patient reasonably is expected to come to the doctor with a common goal of gaining help with their health. A Doctor and patient might not share other goals or values, but at least ought to agree on this one aspect of why they have a relationship together otherwise the relationship is hardly what a professional relationship ought to be.

I have mentioned that “reasonable” might have a minimalist meaning that might not refer to what is based on “rationality” and “Reason” (for example, justifications derived from¹²⁷ norms of logic) but is more based on reasons that might be more affective and less deliberative, such as a reason that one finds something pleasurable. Scanlon writes that for the purposes of the system he argues for that a reason is,

“a consideration that counts in favour of some judgment-sensitive attitude, and the content of that attitude must provide some guidance in identifying the kinds of considerations that could count in favour of it” (Scanlon.T, 1998, p. 67),

Furthermore, Scanlon stipulates that such reasons ought to be what he calls personal reasons rather than impersonal reasons claim that,

“Impersonal reasons do not, themselves, provide grounds for reasonably rejecting a principle.” (Scanlon.T, 1998, p. 220).

Scanlon does not mention that reason pertains to rationality or to some pre-determined normative code. Rather for Scanlon, I understand that “reason” refers to some justificatory evidence for an attitude that is based on a person’s appraisal of a situation. Scanlon is careful to limit reasons as being “personal” to highlight the importance of the interpersonal and relational nature in how we might determine what we owe each other. Such personal reasons might be of particular importance in the context of the ideal doctor- patient relationship where highly personal matters might arise and be a source of disagreement between two individuals. Reasons of the type that Scanlon refers to are important in a moral relationship due to the requirement that I have described that at times one person in a moral relationship with another ought

¹²⁷ The philosophical literature on “rationality” and “reason” is vast and I have not space to provide a discussion of these accounts here. However, philosophical literature on “rationality” is often thought of as pertaining to reasoning and a level of cognition that involves certain norms of logic being applied to various elements of what is believed to be “reality”. Rationality can be associated with belief in terms of justification for that belief and reality. A belief might be construed as being well-grounded if it has sufficient evidential basis in the facts.

to be open to being answerable to the other party. Providing reasons to another can demonstrate a relationship of respect and signals to the other that one cares about what the other thinks. In this manner, care is associated with showing respect. Caring about what the other believes in or values might be felt by the other person as caring about them.¹²⁸ In addition, by providing justificatory reasons for disagreement, where respectful co-deliberation is maintained, there is scope for one or the other person to alter their views in the ensuing dialogue. Without recourse to co-deliberate over contested reasons (not "Reason"), one person might not be able to fulfil their requirement to justify to the other why they are not willing to tolerate a particular belief or a value. Without their views being heard, or their story being attended to that they feel justifies their value or belief, that person may feel disrespected, and the relationship may be harmed or might even end. Scanlon says that in his ideal of process of contractualism there is a,

"shared willingness to modify our private demands in order to find a basis of justification that others also have reason to accept" (Scanlon.T, 1998, p. 5). An attraction of Scanlon's account is that we see that reasons are construed as important in a moral relationship in cases of disagreement, as reasons are the basis for how one person might have dialogue with another person in order to show consideration for the other. Such reasons might be more or less affective or deliberative¹²⁹ and the with co-deliberation two people have the opportunity to determine what reasons are more or

¹²⁸ Where one person feels that they ought not to tolerate a value of the other, that person may (though does not necessarily) demonstrate that- in a sense- they care for the other and have willingness to share what they feel is important to them. Even an enemy is intolerant of someone and attacks them, they show that they care about what they are intolerant of, enough to take action against it. In the context of the in the setting of the schema of the three linked constructs, care may be shown by expressing that a belief or value will harm the relationship or the patient's health.

¹²⁹ By more or less affective I also mean that "Reason" (discussed section 3.6 and 4.2) as determined by norms of logic need not be the only means by which people may find justifications for one another. Small r "reasons" may be more phenomenologically justified or based upon a feeling of for example comfort. For example, in a situation of palliative care, the patient's feeling of comfort may be a well-founded reason to decide upon a therapy.

less persuasive as justifications to one or the other.

Another problem with contractualism might be that of “redundancy”. When Scanlon claims that there is a requirement for personal justificatory reasons for, “moral motivation” (i.e., the reasons for being moral) and the content of correct moral principles (i.e., “what we are morally speaking required to do”)(Suikkanen, 2005, p. 38)) it might be claimed that Scanlon merely re-states assumptions underlying his original claim. That is, the moral claim that is made at the end of an argument is the same as a premise that it started with. The need for reasonableness might seem redundant as it is claimed that what is actually driving the moral argument is some notion of, for example, well-being or fairness. Scanlon predicted this critique and wrote that,

“If we were to appeal to a prior notion of rightness to tell us which considerations are morally relevant and which are entitled to prevail in cases of conflict, then the contractualist framework would be unnecessary, since all the work would already have been done by this prior notion.” (Scanlon.T, 1998, p. 213)

Judith Thompson expanded on the possible objection raised by Scanlon by suggesting that torturing babies for fun is simply cruel and wrong and there is no need for people to justify to each other why, as this is just a heinous act. However, such a claim itself might be seen as “begging the question” as the claim rest on the pre-existing assumption that gratuitous cruelty is always wrong, and it can at no time ever need to be justified (Thomson, 1990).

Scanlon’s response to the question of redundancy in his account of contractualism is over a few pages (and subsequent papers) and he claims that,

“it is misleading to suggest that when we are assessing the “reasonable rejectability” of a principle we must, or even can, set aside assumptions about other rights.” (Scanlon.T, 1998, p. 214). It seems plausible to hold that indeed any person

necessarily cannot come into relationship devoid of assumptions about the importance and nature of, for example, each other's rights or the terms of their relationship. Indeed, I hold that as a fundamental point, morality relates to how people interact with one another. This is an assumption which I make in my discussion about morality. In determining what are ethical ways to base the I.D.D.P.R upon, though it might be an ideal to, for example, cast off all of one's preconditioned ideas about principles and for example adopt "a veil of ignorance" (Rawls, 1999), such an ideal might not be achievable in practice.

As Scanlon also writes, "No theory, whether contractualist or not, can avoid beginning with some claim of this kind. You cannot get something for nothing" (T. M. Scanlon, 2003, p. 180). Any process that people might refer to in determining how they ought to deal with each other requires certain assumptions on which it might proceed. For example, I have claimed that at least a degree of respect is required for people to determine how they ought to relate to one another. Without a degree of "recognition respect" for one another it seems hard to see how any relationship might occur. As you cannot get something for nothing, one cannot have a relationship with another person without in some way being at least aware of their existence and therefore have a level of recognition respect that they exist.

A final issue for Scanlon that I will discuss that might be problematic is that his system in many instances requires people to co-deliberate to be part of a moral process. Such a process of determining what health choice ought to be made might seem to exclude many people (such as minors and people with certain disabilities) from having an opportunity to be heard and respected. However, people such as minors or those who are infirm may have proxy agents or carers who can co-deliberate on their account. In the context of health care this is not uncommon when a parent takes responsibility for

their children's health care decisions or people may appoint those whom they trust to make decisions for them in case they become incapacitated and are not able to make or communicate decisions.

Some people may choose not to co-deliberate. A person might not have a "shared willingness" to sacrifice their "private demands" (see above) nor to provide justification to anyone, let alone their doctor as to what they believe that they ought to value or believe with respect to health care decision. Such a person may appear to the other as belligerent and not caring if they show disrespect to others who feel that they ought to be considered by that person. The supposed "ethical requirement" to be reasonable, or need to justify to others certain beliefs might be an assumption that the "belligerent" person believes does not hold for them. Such a person who claims not to care about others, or what those others think about them, might appear to be absolving themselves from requirements to honour certain expectations that others might (otherwise reasonably) expect to have of them. These expectations might involve certain ethical codes of conduct. For a patient or doctor to suggest to the other that they may absolve themselves from the need to treat the other ethically, might foreseeably have negative consequences for the relationship continuing as a professional doctor-patient relationship. Though a doctor may feel a duty of care even for a patient who grossly disrespects the doctor, such a relationship seems one that might be difficult to sustain and is unfair on the doctor.

A patient may suggest that they may permissibly choose to make an "unreasonable choice" just as may anyone in any sphere of their lives. To say that someone is unreasonable, does not mean that a person "falls out of the tribe" of those whom health practitioners treat with respect and in an ethical way. This is because we still ought to treat such people as worthy of some form of at least "recognition respect", if not

“appraisal respect” in regard to the matter that is considered to be unreasonable. Even if reasonableness were considered to be the basis of morality, a person might not be “globally unreasonable”, but might be considered by some people or themselves as unreasonable only with respect to specific matters. To claim that someone is unreasonable is to state (in the setting of reasonable pluralism) that we are not able to have a dialogue with them in an attempt to reach some understanding and consensus, as such a person rejects the possibility of discourse about a specific subject. A patient who dismisses all attempts at discussion and simply believes in, for example, Shamanic healing and nothing else for their health care, loses the large range of health care options that health practitioners could discuss with the patient, in an environment of “reasonable medical pluralism”. (That is, where a plurality of beliefs and the reasons behind those beliefs may be considered by involved parties.) Health practitioners should not treat the patient in any less moral a way for their “unreasonable belief” but doctors ought to treat them with respect as they would accord anyone else. For example, a patient might be “unreasonable”, and refuse to allow dialogue. However, though a doctor’s treatment may not be able to proceed, the doctor may still have a duty of care for the patient. A patient might adopt an intractable position and refuse to consider usual effective care, for example by believing that a Shaman will heal them to the exclusion of all else. In the model of the I.D.D.P.R that I link to the other two constructs, the doctor still ought to feel compassion and a duty of care with a desire to avert foreseeable suffering for such a patient. With no possibility for one person to justify their position to the other, that person may feel rejected by the other and might feel that the other is intolerant of them. It is problematic that the doctor feels it is important that they show to the patient that they feel a duty to care for the patient and that the patient is intolerant of considering the doctor’s care. Indeed, in the

I.D.P.D.R. the model is patient centered, but this does not mean that the doctor need not be considered as also important in the relationship. It is also problematic for the caring doctor (both personally and professionally) to determine how much tolerance they ought to have for a patient's unreasonable or ill-founded decision that will foreseeably harm a patient. The idea of tolerance is now discussed in the next section of this thesis along with the notion that there may justifiably be thought to be universally applicable moral objectivism¹³⁰ in some matters, even when values and beliefs that are disparate from ours are examined.

3.7 Tolerance and what the patient and doctor owe each other.

If we accept medical pluralism this does not mean that we agree with, leave unquestioned or tolerate all practices. In some cases in health care, health practitioners ought to attempt to curtail harmful cultural practices out of respect for the patient and their situation. Though on first inspection by the patient such attempts at persuasion may seem to be disrespectful and overly paternalistic, I will argue that such attempts at dialogue show respect for the patient through the manner in which the practitioner expresses care for the patient.

Where principles of justice and non-maleficence are being breached, as in for example the case of harmful F.G.C., I will argue that we may rightly not tolerate portraying as health care what is actually cruel, suppressive, disrespectful, or unjust treatment. (Macklin, 1999, Nussbaum 1999). For example, by appealing to the conception of "reasonable tolerance" that I will develop in this section, we are justified

¹³⁰ In brief; The position of moral objectivism might lead a person to hold that some matters of what we owe each other, are moral facts, like physical facts and that their reality is immutable despite differing beliefs between people or cultures.

in trying to educate or “nudge”¹³¹ individuals in a community away from harmful F.G.C., by arguing for the epistemically ill-founded nature of F.G.C., and for legislation against such a practice in our jurisdiction. Individuals of a society may appeal to principles that proponents of practices such as F.G.C. cannot reasonably reject if they choose to live in harmony and abide by principles that society derives by co-deliberation. Health practitioners ought to attempt dissuasion of patients who pursue harmful and ill-founded care on cultural grounds (in some high stakes situations), and not just because of the doctor’s sense of duty to stand by their construal of principles of justice, care, etc. In such situations as mentioned above the I.D.D.P.R may serve as a helpful template for the doctor and patient to determine what they owe each other when one feels that they cannot tolerate the action or inaction of the other.

We may accept medical pluralism and respect many people’s beliefs from diverse cultures and be keen to understand them, however this does not translate into necessarily agreeing with all cultural practices, peoples’ values or beliefs. In more extreme cases such as disfiguring F.G.C., we may adopt a stronger position of not only disagreeing, but not tolerating as there may not always be “room” for compromise. I refer on initial reflection to tolerance as an attitudinal state of acceptance that there exist views or behaviours that one may not like or agree with but that one will not oppose nor have as a basis of conflict.

However, there is more to tolerance than putting up with things we do not like or find it difficult to put up with like the cold. To further explore the nature of tolerance we might gain insight into its nature by considering its opposite, intolerance. Plausibly,

¹³¹ Briefly, a nudge is an attempt to influence someone in order to help them as a part of a theory of “libertarian paternalism”. A nudge attempts to alter the choice architecture of an individual or even a society. This is claimed to be a form of “paternalism” with the ethical debates that surround this area, even though the targets choices are not restricted as “it tries to influence choices in a way that will make choosers better off, as judged by themselves” (Thaler, 2008, p. 5).

intolerance implies a certain disdain that is stronger than indifference to what we accept. To be intolerant of a thing such as the cold differs from being intolerant towards a person or their beliefs, as the latter intolerance may appear, rightly or wrongly, to that person as that you do not approve of them or a part of them, or that in some way you have less respect for them. In such a manner tolerance might be thought of as an attitudinal state that is both based on cognitive and affective factors and has an impact on how we relate to people. As Scanlon explains in his initial discussion about tolerance.

“My argument so far is that the case for tolerance lies in the fact that rejecting it involves a form of alienation from one’s fellow citizens”(T. Scanlon, 2003, p. 194). That is, by rejecting tolerance of a person we distance ourselves from other people and in so doing we might thereby exhibit less “recognition respect” for that person. In this manner tolerance, is a factor that determines the nature of our relationships. However, we may marry someone who retains a different religion to us and respect them while choosing to disagree on a matter. Each spouse might tolerate their partner believing in a different religion to them, even though each person might not tolerate holding that religious belief themselves. While on one level we would then be to a degree alienated from our partner in one aspect of our life, we may consider that this level of alienation does not threaten the relationship as in fact our differing religious views do not make us different from one another in a manner that matters to us. We may recognize that we are different, almost alien from each other on some ways but we may share certain values and other factors serve to maintain our respect for one another. To avert conflict and respectfully live together we may “agree to disagree” on a matter of religion and tolerate each other’s religious views as we share so many other values that we agree upon. To quote Tom Scanlon there may be,

“pure cases of tolerance, in which it is not merely an expedient for dealing with the imperfections of human nature. These would be cases in which persisting conflict and disagreement are to be expected and are, unlike racial prejudice, quite compatible with full respect for those with whom we disagree. But while respect for each other does not require us to abandon our disagreement, it does place limits on how this conflict can be pursued.” (Scanlon.T, 1998, p. 188).

A person may tolerate a thing that they have some disdain for, in order to show respect and recognition that another person has come to views that differ from theirs, not based on any ideas that the other person is inferior, but because the other person has come to a differing understanding that the tolerant person might seek to understand. Whereas I initially referred to tolerance as simply letting other people adopt certain practices or beliefs which I deem are in some way disdainful, tolerance may be construed as more about signalling¹³² respect for other people, even if their views differ from mine. In the setting of the doctor-patient relationship each person may use tolerance to limit possible conflicts about health care decisions. In addition, the patient and doctor may use tolerance to signal to each other respect for each other and determine what the bounds of their relationship ought to be.

The implications of tolerance and intolerance are important in ethics and debate might arise as to what it is possible to tolerate and what ought to be tolerated or not tolerated. There are cases in health care based on the schema of the three linked constructs where the patient's health practitioner ought to be intolerant of significant harm to a patient due to the patient's ill-founded freely accepted beliefs. The health practitioner ought not to tolerate that certain beliefs of a patient, while derived by the

¹³² I will not give a comprehensive account of the term “Signaling” other to claim that this term is used in discussion of the nature of trust Karen Jones writes in her piece “Distrusting the trustworthy” that “Signaling is communicative and takes place against a vast social background including norms and shared understandings of what can be expected of whom”(K. Jones, 2013, p. 190).

patient “freely”, were ill-considered and were not appraised with others who sought to dissuade the patient from being guided by that belief, which will foreseeably lead to intolerable outcomes for the patient and for those impacted by their suffering. The next paragraphs will argue that in certain circumstances, opposition or conflict is what is morally required.¹³³

Tolerance and intolerance are argued by many to be necessary and appropriate at various times in many social contexts. For example, Tony Blair said,

"Our tolerance is part of what makes Britain, Britain. Conform to it; or don't come here" (Woodward, 2006). This was said in reference to religious intolerance, topical for the U.K. and its past civil war, and the so- called “radicalisation of youth.” Intolerance of intolerance is referred to as the “paradox of intolerance” by Popper in *“The open society and its enemies”* (K. Popper, 1966) who argued that we are right to refuse to tolerate intolerance and Rawls in *“A Theory of Justice”* (Rawls, 1999) who argued that we should usually tolerate the intolerant otherwise society would become intolerant of minorities and itself become unjust. However, Rawls seems to qualify this position on intolerance by saying that,

"While an intolerant sect does not itself have title to complain of intolerance, its freedom should be restricted only when the tolerant sincerely and with reason believe that their own security and that of the institutions of liberty are in danger." (Rawls, 1999, p. 220). By this view, tolerance has limits when others are endangered by the actions of a group (or individual) that exceeds what is considered safe for others. In all the above quotes it seems that tolerance relates to what attitude we have to others and will influence how we behave to others. others. Therefore, in the setting of a conflict

¹³³ Just as arguably at times there is such an endeavour as a “just war” as argued by many over the centuries, including Aquinas, Plato and many others.

over a fundamental health decision it is important for a patient and a doctor to determine what either may or may not believe is reasonable to tolerate or otherwise.

3.8 Reasonable tolerance in the schema of the three linked constructs.

Part of the underpinning of the account of medical pluralism that I defend is the doctor and patient's moral requirement for reasonable tolerance of each other's beliefs. To some people tolerance may imply respect for another party at the expense of our own views not being actioned. Tolerance may involve mutual or unequal loss or compromise by either party in order to avert conflict in a disagreement. For Scanlon, such loss is,

"the price of recognizing one's fellow citizens as equal members of society" (Scanlon.T, 1998, p. 3). Further, the need for mutual respect,

"is deeper than . . . conflicts" about "the nature and direction of society". (Scanlon.T, 1998, p. 193). I infer that for Scanlon, contractualism holds that the individual relationship and the maintenance of mutual respect and tolerance between individuals is more fundamental than the societal considerations that are there to serve individuals and their relationships. We may hold various beliefs, but we do not act on all of them, due to our understanding of the need for tolerance to maintain our respectful relationships. To do so may show disrespect or harm others and in so doing harm our interests or the interests of others in our group who share values. In relationships we may hold "our tongue" and (for example) not tell our partner that their haircut is in poor taste. We may tolerate our partner's hair cut or more significantly their different religion for the sake of the relationship. An empirical observation I make, is that we do not always publicly reveal everything we think, nor act on our every belief or desire, in part

as we are concerned about how we affect others and the effects of our words and actions have on our relationship with others, including how we appear to others¹³⁴.

Tolerance seems pivotal to the notion of “dialogical consensus”(Parekh, 1996). By his concept, minorities who have behaviours as part of their sub-culture that the broader community do not accept, come to explain why their practice may be incorporated into the broader community based on agreed “societal public values” (Parekh, 1996, p. 259). Such public societal values may not be privately held by individuals but are understood as the public face of how to engage with others and have a dialogue. For example, a person may find homosexuality unpleasant, or unacceptable for themselves but might accept that other people may live a free life and deserve the respect the same as anyone else, independent of sexual preference.¹³⁵ For Parekh, determining what justifiably may be tolerated or not is based on developing public values that can be agreed to. As minorities shift the boundaries of what is tolerated a society may develop. In this setting it is seen that tolerance is a necessarily a *dynamic* attitudinal state which is adopted in order “to get along with others” and in some cases build society. Dialogical consensus plausibly determines what may be reasonably tolerated for doctor and patient, or a group.

It is illuminating to apply dialogical consensus to how people who utilise more novel health practices may have their health practices more widely adopted by those who are guided by processes of E.B.M. A definition of the processes E.B.M. and more novel health practises and including C.A.M. may see these practices as encompassing

¹³⁴ In the “theory of mind literature” literature mentioned above it is suggested that we consider what others are construing and how they view us.

¹³⁵ That person does not share their possible feelings of “disgust” with others, as to do so may not only be unnecessarily hurtful to others but a person’s disgust in a particular sexual practice may be conflated by others with disrespect for the persons who engage in a sexual practice, even though the sexual act is only one aspect of the entire person.

activities of intersecting Venn diagrams. Some practices have been developed and appraised by processes of E.B.M. and some novel or C.A.M are more fringe and are considered by many as less well-grounded. What is considered as too unreasonable or poorly grounded, and what are health care practices that we ought not to tolerate, may be a subject of co-deliberation. Those who refer to processes of E.B.M. may justifiably tolerate practices that have lower level evidence that are widely practiced¹³⁶ while the area is being researched and so such practice is used with cautious tolerance. Such tolerance is important for the progress of knowledge and rests on hope for a better way of doing things in the future and recognition there may be better ways of care. For example, an E.B.M. health practitioner who adopts a fallibilist attitude may think; “Who am I to say that patients do not have pain relief from acupuncture; we may at least trial it?” Tolerance may be a part of scientific progress (that those guided by E.B.M. aim to be supported by) in that from a viewpoint of Kuhn, science progresses through paradigm shifts (Kuhn & Hacking, 2012) where we try things out to see if they work. Necessarily we tolerate something while we trial it and give it time to see if it works.

Tolerance seems to have associations with time and patience. For example, in scientific epistemology, we may be justified in tolerating a new health practice, or trial drug for a time until quality research results strongly provide evidence that the therapy is not what we hoped for or is harmful. This may be an example of reasonable tolerance that with time crosses over to intolerance. In our interpersonal spheres, we may be tolerant now, but with time we may act out our privately held belief at the right moment, possibly after views of others have changed or we judge that time will run

¹³⁶ For example use of some screening programs in E.B.M., such as prostate cancer screening or some complementary therapies, for example acupuncture with certain caveats discussed elsewhere in this thesis.

out, before something intolerable may ensue. For example, if one's partner changes hair style, and a month later you say; "well actually... but I didn't want to offend you." In the case of religion, with the passing of time, aspects of beliefs of two differing religions may merge or individuals may adopt more or less of one religion and aspects of another. It is plausible to think that, with patience and tolerance, conflict might be averted and over years, mutual understanding, relationships or blending of ideas can evolve, that may have been precluded by intolerance. Using tolerance, one is optimistic about maintaining relationships and averting conflict. Reasonable tolerance in this situation fosters ethical behaviour and mutual respect. Intolerance is more likely and is justified if no possible resolution of differences is seen in the short or long term and the issue of dispute is perceived as greatly important. Thus, our attempts at predicting the future and what we hope for may be important in coming to tolerate some things and not others. In health care it is difficult to predict future outcomes, but expert health practitioners may be better placed than a patient to make more accurate predictions about the natural history of testicular cancer. I therefore argue that when the health practitioner sees such a dire future for the 25-year-old patient if action is not urgently taken then the health practitioner ought to attempt to maintain the co-deliberation¹³⁷ as they may be justifiably intolerant of the patient's belief in the futile therapy and rightfully seek to avert a catastrophic health outcome that is avertable.

Time may be critical where effective care is deferred, as some health matters become irreversible if not dealt with early. A sense of urgency may sometimes reasonably limit tolerance where harm may foreseeably be averted if action is taken early. For example Steve Jobs initially had a relatively indolent pancreatic cancer, that he self-treated with alternative therapies which he found on the internet, until it was

¹³⁷ That is, in the setting of the schema of the three linked constructs.

too late to potentially save him with care based on new evidence at that time (Walton.A.G, 2011). If a patient is about refuse a unique, even slim opportunity for cure, as they take an irrevocable path of futile therapy,¹³⁸ we reasonably expect a health professional to help a patient to see their mistake in their appraisal of the efficacy of a cure.

From the nature of time and tolerance I now turn to consider what professional duty a doctor has in the case of a patient whose health choice oversteps what may be reasonably tolerated by others who will be affected by the patient's decision. In the context of the schema of diagram 1, I will argue here that, based on justificatory grounds that others cannot reasonably reject, the doctor has a duty to attempt to dissuade the patient from pursuing a course of action involving reasonably foreseeable harm.

For example, in Job's case, "His early resistance to surgery was apparently incomprehensible to his wife and close friends, who continually urged him to do it" (Walton.A.G, 2011), that is accept standard medical care. It would seem unprofessional for a doctor who had known Jobs for years (when Jobs presented with his refusal of potentially effective care) to simply show Jobs the door, present him with the bill, and say goodbye. For, as Emanuel argues,

"The ideal physicianis a caring physician who integrates the information and relevant values to make a recommendation and, through discussion, attempts to persuade the patient to accept this recommendation as the intervention that best promotes his or her overall well-being" (Emanuel & Emanuel, 1992, p. 11).

By this model of the I.D.D.P.R., an ethical health practitioner ought to show

¹³⁸ That is, in the setting of the schema of the three linked constructs.

compassion for a patient and try to save their life where there is well-grounded hope (see chapter 4) for a treatment that the patient does not appreciate. Jobs' health practitioners and wife justifiably did not tolerate Job's decision without questioning him, as time was critical because deferring early potentially effective care led to a lost opportunity for cure. It would have been unjust to Jobs had those expected to care for him, not tried to give him a better chance of survival. To uncritically accept Jobs' ill-guided health choice without attempting to dissuade him was intolerable as not only did his health practitioners have a moral duty to show care for him in trying to dissuade him, but the loss was so high, that the health practitioners were obliged to not stand back and watch Jobs make an ill-founded decision. The antithesis of care is to not care for someone, to ignore them in their time of need. Jobs' wife and health practitioners tried to do the "right thing" by Jobs and not tolerate his lethal choice, but Jobs refused to listen to them, and Jobs acted unreasonably towards them in the sense of not attending to their views. If we believe that "what can be reasonably rejected" pertains to what the opinion of others broadly have agreed upon, then Job's intolerance towards considering the effective care he was offered was unreasonable.

Job's cancer advanced and he regretted his decision. Subsequently Jobs had major surgery and medical interventions that were heroic, but these were too late. Subsequently after time had passed and Job's tumour had advanced and was incurable, supporting Jobs in the use of non-harmful C.A.M. that did not defer effective palliative care, may have been tolerable to his practitioners and wife, as it could be felt by Jobs as a type of care. There is empirical data to suggest that for certain patients, use of some C.A.M. in the palliative phase, may help a patient to cope (Sollner et al., 2000) and so it is compatible with reasonable tolerance by the practitioner to make use of some C.A.M. at the end when effective curative care is not available where no

harm from C.A.M can occur. Just as there are differing types of pluralism, it seems plausible to hold that reasonable tolerance exists at differing times and in differing circumstances. The assessment of the future and what potential there is to lose, may be a basis for what people may accept versus what people may be less tolerant of, and may seek to dissuade others of.

Reasonableness in the doctor-patient relationship may be plausibly construed in several ways; as pertaining to how the patient affects others and the patient's current or certain future interests, or to how much the doctor or patient consider the views of others. It is also seems plausible to hold that what is determined as the basis of what is considered reasonable varies with the situation and the circumstances of the people who are involved in deciding what is reasonable.

On prima facie inspection a health practitioner might believe that "rationality" might be the basis for a doctor and patient to determine what ought to be tolerated or not tolerated in determining what we consider is reasonable or unreasonable in the health care setting. A doctor might believe that "reason" is determined by rationality, and they believe that the doctor ought to represent rational thought. Such a doctor might believe that the processes of E.B.M that they ought to be guided by are simply based on principles on rationality. However while processes of E.B.M, do indeed attempt to be guided by rationality as represented by applying norms of logic to the ranking of evidence (for example by trying to account for variables with Bayesian reasoning in R.C.T.) those who use process of E.B.M also count as important more affective and relational aspects that might not always be dominated by norms of logic; such as clinical acumen and the patient's feelings to differing degrees in differing circumstances. In the I.D.D.P.R practitioners who are guided by standard accounts of processes of E.B.M. ought to co-deliberate with the patient regarding what is

considered reasonable. To determine what may be reasonably tolerated or not reasonably rejected in each clinical setting in the I.D.D.P.R., the pair may use respectful co-deliberation to agree upon how much weight to give to a patient's feelings, values and beliefs, the doctor's clinical acumen and types of scientific evidence.

Uncontroversially there are many views of what health care is and some views may be less well-founded on cognitive grounds. However, a physician's duty to where possible, avert unnecessary suffering and death, may be widely accepted as among the duties that a society and patients may reasonably expect of compassionate doctors. A patient who understands the social contract a doctor has to the patient (and society), may expect that the doctor will find it hard to accept, without attempts at co-deliberation, a foreseeably implausible so-called "remedy" that defers effective care in an extreme case. Mutual respect may have a patient understand that a doctor ought to attempt to dissuade the patient from alternative care in some high stakes health settings as in the I.D.D.P.R. the patient ought to recognise that such offering of guidance is the duty of a doctor who subscribes to processes of E.B.M. In engaging with the doctor, generally the patient has agreed to engage with the doctor in certain ways (that might be changed with co-deliberation) and may reasonably be held to hold certain expectations of how the doctor will relate to them in cases of disagreement. Tolerance should be mutual, and the patient at least should "give the doctor a go" in their attempts to dissuade the patient from an ill-founded health choice in a lethal situation because in an ideal relationship based upon the schema of the three linked constructs, they have both agreed to show respect to one another by attending to each other's views.

3.9 Principlism, relativism and how the doctor and patient may determine what they owe each other.

A health practitioner might respect their patient, but this does not mean that a health practitioner should compromise principles of professionalism, beneficence, and justice in favour of a possible claim that a patient should be free to make any health decision they want, including being free to make an ill-founded decision that that will foreseeably bring them great harm and harm others who care for the patient or rely upon the patient. In a doctor patient relationship that fosters co-deliberation there can be dialogue about which principle ought to apply more in each setting and which account of the principle should be referred to by both parties. A patient and doctor might need to decide upon which account of autonomy is more applicable in their situation. There are a number of differing accounts of autonomy, including a more relational account (Mackenzie, 2000) of the patient's autonomy¹³⁹ to a possible notion of autonomy a patient might hold where by what is considered important is the patient making decisions independently and free of interference from other people.

I have discussed how medical pluralism involves recognising that patients and health practitioners may come into a relationship with differing values and beliefs that inform what values they hold. These values in turn may be the basis for them to determine what principles they adopt in making health care decisions, including how the doctor and the patient ought to relate with one another and what account of autonomy they subscribe to. At times, a patient or doctor might pay less or no regard to a principle

¹³⁹ In brief, autonomy may not relate only to what a person considers important now, but what will be important to them in the future. In making an autonomous choice the person may be advised to consider their future selves and interests balanced with their current situation. Relational autonomy sees a person as not isolated in their decision making but part of an elaborate social web who arrives at a decision inevitably with multiple influences that lead to that decision such as their gender, race, class, culture etc.

that the other considers ought to be universally applied in determining what the doctor and patient owe to each other or what health decision ought to be made. However, a patient (or their doctor) is very unlikely to make a significant health care decision in a social vacuum, as others around the patient might be significantly affected by their departure from good health. In this manner, health decisions might typically impact upon others in a manner that many other decisions do not. Though the doctor and patient might share some value and not share others, neither ought to reject that such values might be guiding them to make health decisions that adversely might affect the other or patient's loved ones.

A patient might believe that upholding a principle of valuing freedom of personal choice, ought to be viewed as adequate justification for making a health decision without regard for others. Such a position might be similar to a belief that a health care choice is like a consumer choice. However, the patient's family and doctor might put to the patient that they may not reasonably reject that their relationship was based on a degree of recognition respect. That is, the patient ought to recognise that their family (and to an extent their doctor) might be hurt if the patient is seen to value them less than a patient's value. Furthermore, the patient ought to recognise that they might harm their social standing and what others might reasonably expect of them if they will not consider those whom they are close to. Indeed, a patient's belief that the most important thing to them is "to live a life free of chemicals" ought to be acknowledged by others as important for the patient. However, such a belief might come with moral costs to the patient as they would otherwise have said that ignoring others who regard the patient in a special way is un-ethical behaviour. To flout a moral principle of agreeing to show each other mutual respect while showing outright disregard for the other and what they have agreed to as a basis of their relationship is to let the other

person down. In addition, the patient in such circumstances might let down others who care for them or depend upon them.

I support arguments for the claim that some moral principles ought to be respected through time and by all people and are not relative to that time or person. To fully support an extreme position of moral relativism may be to agree that a person's values, determine what is right for them to believe and how they should behave. By this view, what ought to be "tolerable or in tolerable" is determined by the individual simply saying that what is right for one may not be for another. A less contentious view that is more compatible with the fallibilism that I have argued for in this thesis, sees that a patient's relationships are formative and indeed may influence a person's morality to reflect the community they live in. In such a manner there is the possibility that information can be modified or rejected as a person gains experience and sees other moralities and reflects on what is more relevant to them. This latter account sees that deciding what may be tolerated is a developing process whereby people may be surrounded by differing views that they ought to be open to considering.

Moral relativism in health care may be understood to be on a spectrum. In one form of moral relativism in health care in some less high stakes health care choices (for example the choice of exercise) a patient may justifiably refer to less co-deliberative processes to form beliefs, whereas in certain high stakes situations a health practitioner ought to try to dissuade a patient from making an ill-founded choice made without appraising the offered opinion of others that the patient ought to attend to.

In health care, doctors may justifiably tolerate some levels of relativism held by the patient in certain lower stakes health choices that may permissibly be left without a health practitioner passing comment, whereas in some situations a health practitioner may justifiably feel obliged to point out ethically problematic health care choices, for

example when certain principles or rights are violated beyond what is ethically justifiable. In health care as in other fields,

“A convincing argument against ethical relativism need not conclude that nothing is relative, only that certain types of actions or practices, chiefly, those that violate human rights, are not”(R. Macklin, 1999, p. 24). I understand Macklin’s argument as claiming that there exist ethical universals that may be interpreted in differing ways by different people apart from where people’s certain rights are violated. Applied to health care, respect for justice and equality and non-maleficence might obligate doctors to not tolerate every traditional practice, belief from every culture or website that a patient might decide to trust. Furthermore,

“a conception of justice as equality, challenges the notion that it is always necessary to respect all of the beliefs and practices of every cultural group” (Ruth Macklin, 1998, p. 1). Circumstances determine in each setting what principle may be more salient to uphold and ¹⁴⁰ it is a matter for moral deliberation and discussion for doctors and patients to decide what principles become more important in each decision. However certain principles ought to be upheld as more important than others, as the doctor and patient have agreed to come together as doctor and patient. As such, while the values of each other’s cultures might be important, it is reasonable for the relationship to be based upon the patients’ health care and on a degree of mutual understanding and respect between doctor and patient.

It is not necessarily the case that disagreeing with a patient who makes a lethal health decision is done out of lack of understanding or respect for them or their culture. For example, in the case of a Sicilian woman, (Snow, H.A, 2014) refusing lifesaving

¹⁴⁰ If two people agree to conduct themselves by referring to elements of Scanlon’s contractualism as discussed in Chapter 2.

thyroid surgery for the reason of not wanting a scar on her neck, she initially gave the justification that she believed she had a bad virus as the cause of her respiratory distress, not an obstructing goitre. Additionally, she may have been influenced by the belief that to avert a neck scar was more important than anything else to avert dishonour of people thinking she had been cut by the Mafia. Her cultural background furnished her with this belief and was contributory to impairing her deliberative processes in a manner that she might not have been aware of. In referring to this cultural belief, she may have actually been rationalising her belief to herself and others and so misunderstanding what was dominantly motivating her fear of surgery or confabulating for what was proven to be cognitive impairment.

I do not claim that cultural beliefs always impair a patient's decision making capacity but rather that we may be wise or at times ought to explore the basis for such cultural influences, and why we come to believe that our culture is so important for our sense of identity (Appiah, 2016).¹⁴¹ For example, we might imagine a person, Fred, who grew up in a culture that made it impossible for him to believe anything about the earth's shape other than that it was flat. If Fred were questioned whether the earth were not flat, Fred's grounds for rejecting "such a preposterous idea" might seem well informed for many people in the culture that he grew up in, but most of the current world might suggest that Fred is missing important information that has been denied to him due to the culture he lives in. From the perspective of most of the world's current cartographers, Fred is impaired in his decision-making capacity with reference to the Earth's shape. A patient might be decisionally impaired in an area of decision making as their culture has restricted their "epistemic event horizon" (that is what they can be

¹⁴¹ Briefly, Appiah provides arguments against what he claims might be a commonly held view that a person's identity is necessarily drawn from factors such as their race, religion, culture or nation.

aware of) and they miss out on epistemically important evidence in making what they would consider is a well-founded health choice were they aware of salient evidence that is readily apparent to others.

Returning to the possible association that a patient might make between what they claim are the beliefs of their culture and their sense of identity, a patient might claim that though they agree to much of the I.D.D.P.R. and processes of E.B.M., their doctor may not seek to discuss the values of the patient's culture (as relevant to their health care). The patient might hold certain beliefs or values that they hold are fundamental to their culture or sense of identity and so the patient might offer this as a justification as to why the doctor should not discuss a certain value with the patient. However, the patient ought to not just disregard the doctor outright without at least explaining that this is their reason to not respond to their doctor. Otherwise, the doctor might feel the patient disrespects them when this is not the case. The doctor and patient ought to attempt to agree upon what values they can agree to disagree upon in order to show respect for one another.

However, as I have argued tolerance has limits. A position that a certain patient's belief may be something that is "simply not up for discussion" with the doctor "as it is part of the patient's identity" might not necessarily be an adequate justification for a patient to claim that the doctor should not question the patient about their health decisions. By adopting a fallibilist attitude the patient might acknowledge that their sense of identity might change with new information. Furthermore, a patient's sense of self-identity is important, but should they decide upon a health choice in the manner that Jobs did, their demise due to a health care decision they later regret, will likely affect the sense of identity of others who they ought to care for and to have considered when making that ill-founded decision. For example, a child's sense of self identity

will likely be affected if their mother dies after making a decision that is “simply not up for discussion”

If a doctor and patient were to adopt a position of extreme moral relativism it would be problematic for either of them to hold that all values are always justified for one person, no matter how much the other person may not be able to tolerate such values. If this was the case, the doctor’s or patient’s values, as relevant to health care, ought not to be questioned by the other. An extreme version of moral relativism would render moral debate conceptually impossible. Without some shared values they have no way of coming to agreement¹⁴² and might have difficulty in even initiating dialogue. For example, if two people cannot even share a value of a minimal level of mutual respect, they might see no justification for even acknowledging that the other person is trying to engage with them. However, if doctors and patients can agree upon certain principles, then conflict may be averted as discourse may occur with both “sides” sharing some common ground to base discussion on. In a pure relativist environment where both sides are believed to be “right” and one cannot tolerate another’s actions, conflict may be difficult to avert as there is no starting point for negotiation.

If moral relativism ought to apply to how a doctor and patient conduct their professional relationship, then either party might not feel any need to provide justification to the other party when they are aware that their conduct aggrieves the other or that the other disagrees with them. For example, if a doctor feels that they ought to treat a patient without the usual principles of informed consent as they believe that “Doctor always knows best and is right”, in an environment of moral relativism such a doctor has no obligation to provide justificatory “reason that neither may reasonably reject” as the doctor accepts that they, the Doctor are always “right”.

¹⁴² As might occur in a manner like in Rorty’s “conversation stoppers”.

However, in the I.D.D.P.R., we reasonably expect the doctor to care about what the patient thinks and that the doctor ought to, where possible, engage with the patient in their treatment. Contrary to moral relativism, a doctor ought to be able to justify their position to the patient where the patient initially believes that they ought not to tolerate a treatment and the doctor believes that the patient ought to have treatment. In addition, a patient ought to be able to justify their position to the doctor when the patient believes that they ought to have treatment and the patient is aware that doctor believes that they ought not to be treated.

Borrowing from an aspect of Scanlon's model, the doctor and patient ought to be able to justify their positions to one another in cases of disagreement and extreme moral relativism might make this requirement redundant if both parties "accept" that they are right and have no need to justify anything to the other. If the doctor and patient believe that they have no need to justify their positions to each other the relationship seems to be more casual or remote than we might reasonably expect of a professional relationship. The relationship moves away from being the professional relationship where the doctor and patient respect each other, and where each party considers their impacts on the other, to that of almost being remote strangers who might not have reasons to need to even acknowledge one another.

In the process of E.B.M. where the practitioner ought to consider the patients' values and circumstances and in the I.D.D.P.R. where again values may be co-deliberated upon by the patient and doctor, the professional relationship involves not just a dialogue about medical issues but also a discussion about how to interpret what aspects of value and principles and principle best fit the clinical situation. As in the process of E.B.M. practices guidelines and "best available evidence" do not "tell" patients and practitioners what to do but require interpretation, so too values and moral

principles have now power to “tell” a person what they specifically ought to do or how they ought to relate to others.

Moral principles are most plausibly understood not as the steadfast “categorical imperatives” of Immanuel Kant, but as broad templates to be considered against one another in formulating a moral action. (Macklin, 1999) There may be higher level principles such as treating all humans with equal dignity and respect, or middle level principle such as those enunciated by Thomas Beauchamp and James Childress (Beauchamp T.L, 1994) of respect for autonomy, beneficence, non-maleficence and justice. These principles may be thought to be respected to varying degrees across cultures and interpreted with differing weight depending on the unique situation. In this way principles are not strict rules but give building blocks for moral deliberation and discourse. In a similar manner, W.D Ross argued for a system of weighing up “prima facie duties”¹⁴³ to come up with an “absolute duty” (Ross, 2002) in any one situation and perhaps this may justify health practitioner paternalism in cases of a patient taking on futile, lethal therapy. Ross conceived an incomplete list of seven prima facie¹⁴⁴ principles that generate seven prima facia duties. Such duties are not mandatory but like Ross’s 7 principles act as a guide to moral behaviour. These principles do not by themselves determine objectively what must be done but give guidance as to what ought to be done. In any one situation Ross argued for one principle as being the dominant one, that ought to apply and this becomes the “absolute obligation” that guides moral action.¹⁴⁵ At times principles of beneficence, as enacted by care and respect for the patient, are more important in determining the right moral path for a health practitioner and patient than respect for a tradition that is part of a patient’s

¹⁴³ Such duties may be similar to “middle level principles”.

¹⁴⁴ By prima facie it is meant on initial, intuitive inspection.

¹⁴⁵ For example, a duty of a doctor to protect their patient from readily avertable and foreseeable harm where there are alternatives.

culture.

In dealing with a patient, a health practitioner has an “absolute obligation” to have fidelity to their professional role; to care for a patient, where appropriate to avert unnecessary pain and suffering and respect and agreed construal of patient autonomy by promoting substantial understanding in health decision making. Both practitioner and patient ought to recognize that the basis of the doctor-patient relationship places such relational commitments upon the doctor. A health practitioner ought not to always passively observe a patient defer effective care for futile therapy, out of some notion of respect for the patient’s beliefs that they have derived from, for example their internet “research”¹⁴⁶ or from their cultural background. If a health practitioner is charged with being responsible for a patient’s health care, a Rossian *prima facie* principle may trump a concern to avoid debate or confrontation with a patient’s cultural or other beliefs that promulgate futile care in favour of available effective care.

We may consider what might occur if doctors did routinely abandon their patients to harmful misguided decisions based on ill-founded traditional beliefs, to avoid conflict or mistakenly seeming to be disrespectful to the person’s culture or conception of freedom. If one accepts moral relativism, there seems a possible slippery slope argument to an “anything goes” morality and disrespect of patients may occur justified by a defensive veil of “culture”, “tradition” or personal belief. For example, after ten years of National Socialism, medical experiments on non-consenting prisoners did not depart that much from what was becoming the social norm of Germany. Immoral behaviour was wide-spread and the institutionalised norm and after ten years, became “traditional” for the Nazi culture. Possible “brakes” on such a “slippery slope” may

¹⁴⁶ The term “research” is widely used to refer to people’s web browsing, however, is not the same as peer reviewed published “academic research”.

have been people's attending to their intuitions guided by principles that Ross describes (Ross, 2002) or normative rules or Kantian notions that are anti-relativist. Tradition may dictate to fathers the importance of F.G.C however it is not acceptable to remove girls' clitorises for the epistemologically flawed reasons that are supposed to avert bringing shame to the family. F.G.C has no religious basis but is a cultural practice with faulty epistemic rationalisations for biases that are thought to be based on tradition and misogyny (R. Macklin, 1999; Nussbaum, 1999).

If health practitioners who are guided by processes of E.B.M. did not confront futile therapy based on some cultural beliefs, futile care could continue without restraint. If health practitioners were not sceptical about their own practice and that of others but respected the right of patients to make mistakes or follow harmful health practices of a culture, without ever intervening, horrible things may ensue. Health practitioners in one sense might have an obligation to respect a 25-year old's decision and culture that leads them to defer effective care. However, a patient ought to appreciate that their health practitioner also has an "absolute obligation" to intervene and attempt to dissuade the 25-year-old from what are commonly considered to be ill-founded beliefs that the doctor is not obliged to respect. This may be particularly salient in the case where the 25-year-old is advised that their belief is ill-founded and that it will foreseeably lead to a readily preventable, premature death whereby not only they, but others will suffer. The 25-year-old ought to acknowledge that in coming to the doctor, often for many years, they have entered into a moral relationship of their doctor. For the 25-year-old to snub the doctor's advice and claim that they have no need to justify or reconsider their health decision in light of the doctor's advice is to let down the doctor in what they have agreed upon by engaging in the relationship. The 25-year-old ought not to now reject a principle, for example of showing each other mutual

respect by abiding by their agreements with one another. In an established doctor-patient relationship the two persons involved have in the past agreed to a principle to respect each-other in manner that they will behave to each other in certain ways. Even in a once off professional encounter with a doctor, where the patient is not seriously impaired, a patient ought to recognise that the doctor is engaging with them in a way that obliges the doctor to behave towards the patient within certain professional boundaries. Without the patient showing any justification to the doctor as to why they now disregard the doctor, it is unfair to the doctor who has on some level dedicated themselves to the relationship and might indeed have deferred other aspects of their lives ¹⁴⁷ for the sake of the doctor-patient relationship. In the I.D.D.P.R., the patient is wrong if they were to claim that any degree of relativism ought to be tolerated by the doctor towards the patient without the patient needing to justify such a position. The patient could be interpreted as conveying to the doctor that the patient is a “special case” to whom a principle that they consider others ought to follow, need not apply to the patient. Such a position ought to not be tolerated by the doctor, or patient’s loved ones as it is unfair to others with whom the patient shares a moral relationship.

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3.10 What a doctor owes to a patient who make decisions that will foreseeably lead to significant patient harm by refusing to consider effective care and what such a patient owes to the doctor and those who care for the patient.

I will lead into this section by imagining two clinical cases; one that can be approached by using more standard bioethical frameworks that may assist clinicians

¹⁴⁷ A doctor might have deferred some things at great personal expense, such as her timing of having children to complete her exhaustive medical training. Or a doctor may have deferred other things, such as spending a lot of time with this patient, rather than other patients, or getting to their child’s school event on time. A doctor might allocate a lot of thought and the doctor’s emotional resources to this patient, at the expense of others.

in deciding how they ought to relate to such a patient, and the second case, a slight variation of the first, that may elicit more contentious responses from patients, clinicians and bioethicists.

In the first case I ask the reader to reconsider the case of a 25-year-old who has curable testicle cancer and seeks an alternative medicine cure, (but not suicide). Such a patient wants to live but is misguided or deluded about the best means of achieving this goal. In such a case, an argument may be made that the doctor ought to ¹⁴⁸ attempt to dissuade the patient who is misguided by their error, and in so doing the health practitioner promotes what the patient wants, i.e., to survive. As Julian Savulescu has argued, a plausible claim (I will not discuss further here due to the confines of space) may be made that in certain circumstances a doctor ought to highlight to a patient that their health decision is ill founded as it based on an irrational or incoherent belief (Savulescu, 1997). However, if the doctor attempts to dissuade a patient by just “giving the latest best scientific evidence” the patient might feel that his doctor is attacking him and might further feel that “this attack” vindicates his belief that many doctors are lackeys in the thrall of “drug companies” and “just want to prescribe drugs”.

I will argue that in the setting where both parties have agreed upon the schema of the three linked constructs, a doctor may in some circumstances permissibly seek to challenge a patient’s ill-founded beliefs, and that the patient ought to consider such attempts at dialogue not as an attack on them, but as part of the co-deliberative process that is expected of the relationship. I acknowledge that less ideal doctor-patient relationships exist and indeed in such relationships it may be hard for a doctor to argue that the patient owes them much other than the recognition respect that one

person ought to give another. Though a patient may decide that they no longer want to continue the relationship that they have agreed to, to do so might come at the cost of showing less recognition respect to the doctor and might signal to others that the patient might be less reliable in some aspects of what others expect of them. The patient ought also to recognise that such an impression of less respect towards the person who thought that they were the patient's doctor might make the doctor feel less valued by the patient. Though indeed the patient's health needs are rightfully the basis of the I.D.D.P.R, the patient ought to acknowledge that the doctor is a person, not a mere instrument that they may readily simply discard. To simply discard the doctor like a utensil denies the doctor recognition respect and so wrongs the doctor. It seems uncontentious to claim that it would be wrong for a patient to regard the doctor as an object that has not the capacity to feel and think (at least in some ways) like the patient does.

The case may be modified to be a second case of young man with testicle cancer who chooses to defer effective care, on the grounds that he "would rather die than have chemotherapy". This case differs from the first case as in this second case the patient states that his values are to choose death rather than chemotherapy. That is, the value that he attached to living is less important to him than the value that he attaches to being what he terms "chemical free and natural". In the context of the ID.D.P.R. a doctor ought to question the patient about why they prioritise one value so highly over the other.

While it might be argued that a health practitioner ought not to seek to change a patient's core values, there may be a spectrum of values which are arguably more or less "core" to a patient. A doctor may reasonably expect that if a patient comes to them as a doctor, then the patient expects them to behave like a doctor in a manner such

as aspects of I.D.D.P.R. of Emanuel and Emanuel and to engage in shared decision making with the patient. A patient ought to expect the best possible personalized medical advice. The best medical advice may be that a traditional cultural practice is averse to health, and so a health practitioner ought to at least offer discussion of such advice.

In the above modified case two, a patient would choose a cure if it was “natural” but will not have chemotherapy as it is “against what their life stands for”. I have mentioned how health practitioners who are guided by processes of E.B.M. are supposed to attempt to understand the patient’s unique feelings beliefs and situation. Should dialogue be accepted by a patient, the health practitioner may reasonably ask the patient why aversion towards chemotherapy is so important to them that this value trumps other values. The doctor while trying to co-deliberate with the patient about their health care values might not be very persuasive by just “giving” the patient the best scientific evidence and by advising the patient that there is no scientific evidence that a certain natural therapy works. Whereas the doctor might be more persuasive by appealing to more general and moral arguments in ways that the patient might feel are more persuasive as such arguments are more fitting what a patient consider they ought to attend to. The health practitioner might refer to an expression to give an illustrative analogy “Don’t let perfect be the enemy of the good” ¹⁴⁹ in that the doctor may suggest to the patient that the patient ought to not let striving to perfectly follow an ideal to avoid chemicals (and be “as natural as possible” ..though I am uncertain what this means), destroy other versions of “the good”, such as their survival. A health practitioner may also argue that a patient should consider their other life goals, such

¹⁴⁹ This saying may have derived from Voltaire: “The best is the enemy of the good.” From “*Dictionnaire philosophique* (1770 ed.) ‘Art Dramatique’: ‘Le meglio è l’inimico del bene’

as living to see their children grow up and being able to care for their spouse in old age, or to avert having their family witness them die in pain over months or avoid the use of un-natural palliative care drugs that have some toxicities which are not dissimilar to chemotherapy. In this manner the doctor is trying to engage with the patient to ask them to reconsider their values with relevance to averting chemical at any cost. The patient might counter that they believe that life is worth living only if they live by their ideals, and that though seeing grandchildren and caring for their spouse in old age might be important, the ideal of averting the use of chemicals is more important.¹⁵⁰

While a patient's ideals are important to them such ideals ought to not necessarily solely determine what a patient ought to decide where other people are foreseeably involved in their health decision. Where the patient can see that others might be significantly harmed by their actions, the patient ought to at least consider those with whom they have a relationship of the kind where the patient is reasonably expected to care for the views of others who are close to them. Out of consideration for others who care for them or in some way rely upon them, such a patient ought to not reject their ethical duty to show respect for such others and at least consider their family's (or doctor's) pleas to engage in co-deliberation and allow that the other person remains a part of their life. Rather, the patient ought to attempt to find ways to be able to justify their position to others where requested, rather than allowing for the possibility that they are giving others the impression of being shunned and not valued by the patient.

¹⁵⁰ It can be claimed that people "need to believe" in an ideal (Bering, 2012) and that part of what defines our humanity is our ability to follow narratives, or ideals (Harari, Sapiens, & Noah, 2011) - to the extent that we build cathedrals or go to war as no other animal does. However people may follow ideals to the extreme (Berlin, 1998) and bring on themselves great harm. Not only might the patient harm themselves, but they may harm others who care for them who foreseeably will also suffer if the patient suffers and dies. A persons' emotions or "need to believe" might form a person's self- justificatory reasons to harm themselves, or those around them by accepting an ill-founded health decision.

Ideals are important however the patient ought to show a degree of recognition respect to those whom they owe it to as such respect is important in our ethical interactions with others.

We ought to not just disregard those whom we know rely upon us without some consideration for them as we might not reasonably reject that we ought to be able expect that we can rely on others who know that in some way we rely upon them. Such expectations are particularly important for what the doctor owes to the patient. In addition, in the model I.D.D.P.R the patient owes the doctor to not just honestly inform the doctor of her/his history required for the diagnosis, but the doctor also relies upon the patient to inform the doctor what is important to the patient and to co-deliberate not just over what evidence is relevant but what values ought to apply in the patients' circumstances. It is unreasonable (in the sense that the patient will not provide justificatory reasons) for a patient to deny that their suffering might not readily cause suffering to others whom they have acknowledged or ought to acknowledge rely upon them or care about them.

By consulting their doctor, the patient ought to acknowledge that the doctor relies upon them in ways that are determined by what the doctor and patient have determined is the nature of their relationship. At a minimal level, the doctor relies upon the patient to turn up to an appointment. In a manner the doctor is placing themselves in a vulnerable position (see chapter 5) to the patient as the patient may or may not turn up for the appointment. On a broader level, the patient ought to realise that the doctor cares about what the patient does and thinks about in relation to the professional relationship; for example, as evidenced by keeping appointments. In the

case of a mother and her vulnerable infant, though even a baby might not verbally convey to the mother that the baby relies on the mother, we expect the mother should recognize on normative grounds that her baby relies upon her. In both examples the baby and the doctor both in differing senses rely upon the mother and the patient. In part as the doctor and baby are to differing degrees reliant on the other, they on some level “care” about what the mother or patient do and believes about them. Though I do not disagree that on first inspection the patient is the one with most investment in their own health decision, by disregarding the interests of certain others the patient might show them less respect than they are due and that they have in the past shown respect to by having a relationship with them.

3.11 Patients do not always have a right to choose health care without reasonably considering others who care for them or without considering the interests of others who rely upon them to remain as healthy as they can.

On first inspection it might seem hard to argue with someone who chooses an alternative medicine and rejects outright the advice of their doctor. The person might suggest as a justification to others that their health decision represents how they choose to live, and that it is their right to do with their health as they want. A further justification that they offer might for example be the claim that an alternative health practice is a necessary part of their religion or culture that they believe they ought to follow.

Freedom and the right to follow a religious faith has been part of tolerant pluralist society since the time of John Locke, 1689 (Locke & Tully, 1983). In my experience of clinical practice, standardly health carers accept and do not debate that a Jehovah's Witness may choose to refuse blood products as she/he does not believe in receiving

blood due to religious convictions. However, accepting that someone has a right to believe in what religion they choose, does not necessarily entail that we must also accept without debate, at specific times not just the basis of such beliefs, but that there exist positive rights to be provided with particular health care interventions. By positive rights, I mean that by claiming to have such a right, others owe it to that person to provide them with something. For example, a person might claim a positive right that the state owes it to them, to provide them with at least basic health care health care. A health practice may accord with religious doctrine however some practices construed as health care may not be plausibly regarded as health care but rather are better regarded to be as religious practices.¹⁵¹ I now argue that in a pluralist society, people do not always have a “trumping” right to uphold all traditions or act on all their private beliefs, particularly in matters of health. A patient’s ill health might have been averted by them attending to care that was derived from processes of E.B.M. that they deferred because the alternative treatment that they chose was more in accord with their religious values. I will discuss how this patient’s foreseeably avertable poor health outcome might cause others to suffer whom the patient ought to consider if they choose to shun the advice of their doctor or others whom they ought to acknowledge care for them or rely upon them.

Some might argue that to accept that there are “rights” and that people have “free choice” that others must respect, also means accepting that a person should be free to follow their religion and has a right to make any health decisions based on that religion. In a simplistic version of a classical liberal view, a person has a right to be free to act as they want, if they do not harm or impair the liberty of others (Mill, 2011).

¹⁵¹ Furthermore, some practices that are not religious but “traditional” such as F.G.C. can become a health care problem as doctors must care for the consequences of such harmful traditions.

Such a liberal may argue that the matter of a patient's own health is a private matter, and should the patient make an error in health care judgement then that is their business and that is the price we pay for such freedom (Engelhardt, 1986). Arguably, some accounts of freedom allow for people to be free to make wise or unwise, ill-founded or well-founded decisions, and in so doing require the person to be more or less considerate of others. While all of the above may or may not be the case, it is undeniable that a patient's "free" decisions might impact other people. Other such people might be the health practitioner or others who care for the patient in other ways. In the model of the I.D.D.P.R. though indeed the primary consideration is the patient's health care, such a value ought not always to be upheld at just any cost to others. It is plausible to hold that, because the patient exists in a social context values such fair resource allocation amongst the patient's community or what duties the patient themselves might consider to be important to others, can justifiably influence the degree to which the patient (or others) consider that the patient's health care is the sole focus of the doctor-patient relationship. The model of the I.D.D.P.R. promulgates as the ideal that a doctor and patient ought to co-deliberate on certain values as relevant to health care. One of these values might be to discuss what burden a patient may impose on the rights of others when the patient is adamant that they want to have or reject a treatment on grounds that the patient is aware their health practitioners and family consider to be ill- founded. In the I.D.D.P.R, the patient ought to appreciate that the doctor feels a duty of care for them, as this is accepted by both as the basis of the relationship. If the patient is reasonable (in the sense of willing to consider the views of others such as their doctor) the patient might appreciate that their health decision could burden their doctor and others who care for them should they suffer from an ill-founded health decision. To make a "free decision" without even considering those

that the patient knows care for them (such as their doctor) seems to not acknowledge that such carers bear such care with a cost to them.¹⁵² One of the costs might be that others have forgone aspects of their freedom to care for the patient. Lack of acknowledgement by the patient of such people for the patient, might be felt as a mark of disrespect towards those whom had thought that the patient respected them. The patient in exercising their right to be free to make an ill - founded health decision, might not only burden others in a way that reduces the freedom of those who care for them, but might also be acting wrongly as they let others down who thought that they had more respect from the patient than what they are shown. Though a patient might claim that their notion of freedom allows them to make any health decision, the patients notion of freedom does not excuse them from acknowledging that they might harm and disappoint others in the exercise of their “freedom”.

Accounts of free decision and appeals to a person’s right to live by such decision had European origins in a reaction to the dogma of the certain churches. Kant saw enlightenment as “man’s emergence from his self-imposed nonage”¹⁵³ (Gay, 1973, p. 70). The hope was that each person’s (independent) ability to Reason¹⁵⁴ would free her/him from being told what to do by church, state, and doctor etc. Enlightenment was argued to come from “Reasoning”¹⁵⁵ to make one’s “own” decisions. An application of this view might be that an individual’s health care decision is a matter of private decision for that individual to determine, as no one else may curtail that freedom. According to this view, each person ought to be independent and

¹⁵² The cost might pertain to the empathy or compassion that is expected of doctors and those who care for the patient, see section 4.7 for a discussion on empathy and compassion. Empathy in particular involves sharing some of the other’s suffering and therefore can incur a cost to the one who gives empathy.

¹⁵³ “Nonage” refers to a period of being “not of age” and not yet legally responsible, whereby it is assumed that one needs guidance due to immaturity.

¹⁵⁴ By Reason in this context, I mean the use of norms of logic and the application of rational thought as compared to “reasons” discussed on section 3.6.

¹⁵⁵ See sections 3.6 and 4.2 for my explanation of “Reason” as compared to “reasons”.

free to be able to determine how they Reason and what reasons they need to give to others. By this view, a patient may justifiably reject the guidance of doctors as an example of being treated as if they are in their nonage and suggests that a patient has a right to make their own decision without interference. However, “being free” need not imply that a person always should be totally independent from other people and their guidance.

Patients might not have acquired the skills to independently appraise evidence well in specific health areas and may require help to acquire therapy and evaluate evidence as relevant to them. It is unlikely that Kant would regard all instances of seeking the advice of experts as fostering people to revert to their nonage, or indeed that nonage is such a bad thing in all cases. After-all, particularly if we adopt a fallibilist attitude, we accept mentors, teachers and even the works of philosophers as justifiably guiding us. The Latin derivation of the word “patients” refers to “those who suffer”. We are often not patients by choice, we all sometimes feel (or are) vulnerable or less expert in some fields and so seek guidance and care. However, despite observations that a patient might be impaired in their decision- making processes or might “need” expert help to understand their situation, a patient may reject such guidance and claim that it is their right to act freely, whether well informed, impaired or not.

If respecting an individual’s occurrent freedom is always the dominant principle in determining the moral justification of an act, it seems that a Jehovah’s Witness may be taken to have a “right” that we must respect, to refuse a blood transfusion to save their life, on the grounds that it is their life to do with what they choose. By this account of what person ought to choose, a patient has a right to refuse a lifesaving treatment without considering the interests of others. The exercise of such a right might be seen by the person as an expression of their freedom to choose without reference to or

consideration of others. Even if we embrace a less atomistic¹⁵⁶, view of autonomy it might be argued that though the immediate family may be harmed by the mother's death, the wider Jehovah's Witness community is honoured and strengthened by members abiding by the church's doctrine. However, there is an extensive literature that aims to challenge a fully liberal position that I will not discuss here for constraints of space, other than to suggest that individual freedom of choice, can seem to be a narrow way of determining what is always morally justifiable. It may be a more justifiable position to suggest that patients have a right to free choice, as far as they may choose freely, free from direct duress in the context of their economic position etc. However, the freedom of one person might impinge another person's freedom (and some of the patient's future interests) so if a patient appeals to their right to free choice as their justification for any choice that they might make, their family and carers may plausibly argue that a patient ought to consider how the patient's choice impacts the rights of those who care for the patient.

When making a current health decision, a patient ought to some extent consider what their future interests might look as effected by their current health decision. For example, we might standardly advise those we care for to make lifestyle adjustments for their future interests. Such advice is justified as being prudent advice for the patient. In such a manner it seems that we acknowledge that some of the current patients' rights (to drink a lot of alcohol) ought to be in some way be curtailed as we can plausibly predict what will occur to the patient if they continue their heavy alcohol use. Not just health practitioners, but those more generally who care for the patient may be

¹⁵⁶ In brief, the term atomistic in relation to autonomy I gather refers to a notion of autonomy that sets people as highly individualistic and detached in their needs from others or indeed construes people as competing with others and primarily self-interested. This is contrasted with a more relational account of autonomy that places each person as not only deriving their autonomy from many sources and influences but also I suggest as construing that we depend upon others around us for our autonomy and sense of identity, and that they depend upon us.

expected to standardly consider the interests of the patient now balanced against their foreseeable interests in the foreseeable future. This is not to say that every future eventuality ought to be considered by the patient and doctor, but that aspects of the patient's future may be a point of co-deliberation as relevant to current decisions. What is deemed to be a prudent health decision for one might not be for the other. However, if another person whom the patient ought to respect feels that their rights are being threatened by the patient decision then, if the patient is to respect that relationship, then the patient ought to consider the rights of others who are affected by their health decision.

Letting oneself come to harm and die by refusing a blood transfusion may not directly undermine anyone else's freedom, but it might indirectly undermine the freedom of others and importantly, be disrespectful to others and harm them. If we assume for the sake of this argument that it is plausible to hold that we are social beings and need various levels of relationships with others, it might be a rare thing to find when one person's "free" act in a high-stakes health decision never has some effect on the freedom of others. A Jehovah's Witness mother's right to religious freedom, in choosing to avoid any blood product while knowing that she likely will not survive without such treatment, will likely to some degree undermine the freedom of others. Her children will no longer be free to come to their mother for nurturing or guidance after she dies.

The question arises in such a clinical case as to whose rights ought to count as more important and who has more to lose. It is an empirical claim that needs no justification to say a mother's dying (usually) harms her children. It is a debatable claim to say that harm is greater to her children, as her death is so avoidable, and is unjust for her obeisance of a dogma to the detriment of growing a loving relationship with her

children. If the mother lives by having blood products, and revises her important religious belief, this might come at a great cost to the mother, however it is not clear who has more to lose if the mother lives or dies in these circumstances, the mother or the children. The great cost to the mother of not living by her religious belief could possibly be reduced in time should she adopt a fallibilist attitude and believe that she could alter her core beliefs, interpretations of scripture, notions of self-identity. The mother will never have an opportunity to reappraise her values or sense of identity as she could if she lived to see her children's lives unfold. If she dies the children will never again have their mother.

The mother's "free" act might impact others, and it might be debated that the mother while alive ever ought to be truly free from her duties and responsibilities to her children. It seems to me that it is unclear as to how "free" any person actually is and thus how a claim that a patient's free decision ought to trump the ethical expectation that the patient ought to at least show respect to by considering certain others when acting "freely". For centuries philosophers have debated conceptually what is meant when we say an agent is free to make a decision. Freedom may mean "devoid of coercion or force" but it is uncontroversial that there are different levels of freedom, with total freedom of choice at one of the spectrum (that would seem implausible) and freedom with levels of restriction at the other end. Furthermore, a person may feel free, but plausibly this feeling may be deluded or biased. I do not argue that all of what we believe is determined from external forces, but that we may be influenced in beliefs we hold. Freedom (to for example make a well-informed decision availed of differing sources of evidence) seems limited if room for reasoned deliberation is deflected by an unquestioned explicit bias and/or unknown implicit bias, as when new evidence arises, the bias may impair new evidence from being appraised.

Such bias might trap a patient in one dogmatic paradigm and curtail chance for the appraisal of new beliefs. Freedom of choice suggests that a person has independence to choose something but does not mean that such a choice must be made with more or less cognitive, affective, or co-deliberative sources of evidence. However, one meaning of freedom might be that a person not only may choose options without certain restrictions but that they also are able to use what means they determine to make a free choice or decision. For example, one account of freedom might hold that a person is free “when they can follow their dreams”, while another account might hold that freedom involves a person being able to have the skills to use cognitive processes to break free of a “self-imposed nonage”. A person’s particular emotion might mislead them as it is in part derived from ill-founded beliefs and some of their beliefs might be misleading as such beliefs are in part derived from ill-founded emotions¹⁵⁷. In this manner, an un-examined bias or prejudice (founded on an ill-founded beliefs) may impair a patient’s freedom to make a health decision without the influence of factors that they would normally have wanted to have been aware of and further deliberate upon.

After all, in the model of the I.D.D.P.R a role of the health practitioner is to support a patient to question what health beliefs ought to be considered as being more credible based on what values should be considered here. In support of this last claim, Emanuel and Emanuel’s notion of autonomy as occurs in the I.D.D.P.R. urges self-awareness and dialogue as suggested by the following quote,

The conception of patient autonomy is moral self-development; the patient is empowered not simply to follow unexamined preferences or examined values, but to consider through dialogue, alternative health-related values, their worthiness

¹⁵⁷ “Ill-founded emotions” are discussed in section 4.2 E

and their implications for treatment (Emanuel & Emanuel, 1992, p. 2222).

That is, patients and doctors ought to engage in dialogue, not just about medical data, but also about how such data ought to be considered in light of “examined values” and “unexamined preferences”. A patient may hold a value strongly, however in the above model they ought to be empowered to be flexible and be capable of examining that value.

In certain respects, a patient might be “more free” if they have increased power to examine their values and biases, as they might thereby be more secure in their conviction that the value is suitable for them. Furthermore, in the manner that their departure from good health may reduce a patient’s opportunities (as discussed in section 2.5.1), should a patient make a health decision they subsequently regret which was based upon their former “unexamined preferences” or implicit bias, the patient might feel that their reduction in freedom due to ill health was due to their being unaware of their past implicit bias. This patient may realise only in retrospect why their doctor was trying to persuade them to recognise that they were influenced by an implicit bias that was reducing not only the patient’s freedom of choice, but also the freedoms removed from them by their subsequent ill- health due to an ill-founded health decision. Particularly if a strongly held value impacts on the patient’s health in manner that might greatly affect others, a patient ought to engage in dialogue with their health practitioner about that value so that they have the opportunity to reflect on what others consider what might to them be “unexamined preferences” or even “examined values”. Such co-deliberation hardly needs to be seen as a threat to the patient’s freedom to make a health decision as it is part of the dialogue of the I.D.D.P.R.

A doctor’s attempts at co-deliberation with a patient need not be seen as an attempt

to threaten the patient or their claim to a right of free choice, however if the patient places such great value on the freedom of choice, they ought to respect that others might feel that they also have certain rights that the patients' claims foreseeably impact. If the value of freedom of health care choice matters above all other principles or values, the patient cannot reasonably reject that their freedom is not less important than the freedom of others. The patient who values freedom so highly, acts wrongly if they refuse to even acknowledge the concerns about the rights of certain others as the patient is unfairly applying one rule for themselves and another rule for others.

I question the idea that in health care there is always an absolute "right" to free choice. It is widely believed by many people that "rights imply responsibilities". For example, in his third chapter of his book *"The Foundations of Bioethics"*, Engelhardt discusses the "Right to do wrong", and he mentions the autonomous right of individuals to "cede medical welfare rights in favour of autonomy rights"(Engelhardt, 1986, p. 91). To illustrate this, Engelhardt gives examples of Christian Scientists shunning psychiatry and Jehovah's Witnesses refusing transfusions. With respect to claims of rights or obligations Engelhardt suggests that,

One should attend with great care to the justificatory lineage of all claims with regards to rights and obligations, as well as to what is right or wrong to do. One should act as if all such claims came with footnotes to their justification (Engelhardt, 1986, p. 92).

In this manner I infer that rights are always linked to caveats. Such caveats might include considering the rights of others. Borrowing from Engelhardt's need for footnotes when claiming rights, to determine what the most ethical path is, the "right" of the mother to refuse blood products when "medically needed" may plausibly be thought to require justification from various principles other than just her freedom to

practice religion. To say, “It’s my right to have or refuse a health practice” might not convince others that they ought to contribute to that right being fulfilled, or have their rights impacted or might not seem respectful to them. For example, borrowing from parts of Scanlon’s work, ethical behaviour might be construed by a doctor or patient as requiring some “appreciation of the other”. Appreciation of the other may be seen when one person departs from what is expected of them by the other, and the first person is responsive to the second person’s signalling.¹⁵⁸ The second person might signal to the first that they ought to show respect for the other and justify what is unexpected or was not agreed upon in their relationship. Even without “signalling” by the one who is possibly aggrieved, it seems considerate of the first person (and so is a mark or respect) to try to predict the other’s discomfort and to attempt to provide them with justifications to ease their possible discomfort. As argued above, the rights of the mother’s children and certain others may require consideration and principled debate to determine what is a morally justifiable way of treating all parties.

I have argued that the rights of the patient ought to be balanced with the rights of the family and loved ones, whose rights or freedoms may be reduced by a patients’ actions. There is also the matter of a health carers’ rights (and the community views that they may represent) to not be supportive of what those who are guided by processes of E.B.M. view as futile therapy that will cause to great harm. Though I agree that the “doctor’s rights” are not the dominant factor in determining what a patient may choose, we do not generally expect that doctors always support what they find morally wrong or epistemically ill-founded, (arguably) as we recognise that doctors have a conscience, just as patients do and additionally are bound by professional standards. The following quote provides an example of such a claim.

¹⁵⁸ By signalling to another, I mean make the other person aware in some form of one’s awareness of them.

The patient's right of self-determination does not automatically imply that the physician should also respect and comply with a patient's desire to take other measures, especially if these are contrary to the physician's professional "autonomy". Society respects a doctor's decision to refuse to comply with a patient's request for, e.g.... the prescription of narcotic drugs for recreational purposes (Lynöe, 1992, p. 223).

This last quote refers to doctors not complying with a patient's request for treatment that the doctor feels they ought not to give, whereas in the case of the mother refusing the doctor's treatment, no request is being made of the doctor that the doctor feels they ought to refuse. However, in the case of the doctor not agreeing with the mother's refusal of treatment and the doctor not agreeing to prescribe what the patient wants there is a fundamental disagreement between the doctor and patient. Such a disagreement in a significant health decision makes the model of the I.D.D.P.R. highly relevant if this is what the doctor and patient recognise as the basis of their relationship. In abiding by this model, the doctor and patient ought to acknowledge that one of the professional roles of the doctor is to attempt to facilitate dialogue over what values ought to be applied as relevant to health care. Though Emanuel and Emanuel did not discuss "rights" in their paper, an aspect of the relationship might be for doctor and patient to discuss how each other's rights may impinge on the other's rights. If the patient is aware that this model of I.D.D.P.R. is what their doctor feels bound to as the basis of how doctor and patient ought to relate to each other, then the patient ought to appreciate why the doctor feels obliged to discuss the role of blood products when the patient has refused them.

In the I.D.D.P.R. if a doctor believes strongly that they have a duty to attempt to avert a patient's catastrophic choice, then though the doctor has "no right" to make a

patient listen, and certainly has no right to force the mother to have blood, a doctor may reasonably expect that a patient, may be receptive to attempts at dialogue in an environment of mutual respect, trust and dialogical consensus.

Carers justifiably respect a reasonable level of pluralism and a patient's "reasonable" right to free choice, accepting that there may be limitations to freedom due to health issues, economic circumstances etc.¹⁵⁹ Furthermore in high stakes health decisions, where there is doubt that the patient's decision is freely made due to the likely presence of implicit bias¹⁶⁰ that they would ordinarily want to be made aware of, an attempt ought to be made to engage the patient in a dialogue about their potentially misguided beliefs. This dialogue is undertaken out of care and respect for the patient and for reasons of participating in a moral system that seeks to have agents justify their actions to others according to principles that cannot reasonably be rejected, that have been arrived at by co-deliberation (Scanlon.T, 1998).

In watching the Jehovah's Witness mother bleed to death, although the doctor is not being forced to act to do something that they feel they cannot do (such as forcing the women to have intravenous blood) they are nevertheless left pressured to stand by and watch an avoidable death and care as they may for the patient. Not only the doctor, but even more so some of the patient family may suffer from such an experience. Should a patient allow (even an impression of) co-deliberation, then at least the patient may allow the family (in the case of Jobs) and doctor to believe and to feel that they have tried their best to save a patient from a lethal choice and fulfil their duty of care. The patient may reasonably be expected to understand that their children, loved ones and carers will suffer watching them die, and for a long time

¹⁵⁹ For example, non -egalitarian resource distribution may mean not all people in our world can access best health care.

¹⁶⁰ Bias is discussed in section 5.8

grieve, living with the memory of her early death. The patient might also readily understand in such a context that their doctor feels obliged to show care for them, by initiating dialogue that may provide the patient with an opportunity to re-appraise some of their healthcare related values in light of what they reappraise that they might owe to others. Should the patient allow (even a modicum of) co-deliberation, the patient shows the family and doctor respect and is respectful to society, by engaging in the process of dialogical consensus that has allowed for their religious freedoms.

Even if it is thought that I have not established that patients have no right to refuse attempts at reasonable dissuasion by family and health practitioners, I hope to have at least demonstrated that the patient has a duty to their family and carers to show them respect by at least trying to understand why the carers have come to different health beliefs to the patient. The patient owes it to their carers and family to accept dialogue as the patient ought to acknowledge that their refusal of treatment is of great concern to the family and carers. Such concern ought not to be disregarded by the patient, as to do so might be seen by the carers to ignore that the rights of others whose rights might be impacted by the patient's health choice. For the patient to not recognise that certain others might feel that they have rights to be at least acknowledged by the patient, can be seen as disrespectful by those who thought the patient respected them. The patient owes it to these people to at least acknowledge their concerns.

Chapter 4: The ethical use of hope in health care.

4.1 Introduction

If hope is important in aspects of health care, then I argue that it is important to recognize that hope may be used in more ethical ways or less ethical ways by a patient and a health practitioner. I initially discuss accounts of hope to highlight what hope is and is not, as awareness of the difference between hope and other emotions or feelings can assist a patient and doctor to determine what they should hope for with a patient's health care. What both parties hope for in the doctor-patient relationship and in patient care can not only have major implications for the patient's health but also for their relationship and for those who may be affected by the patient's health outcomes. For not only reasons of prudence for the patient's health but also for what obligations are owed to others, it is important for the doctor and patient to attempt to be reflective on the nature of what they hope for in health care, and on how they come to have such hope. The patient and doctor owe it to each other to co-deliberate on well-grounded objects of hope for the patient's health, and a doctor ought to assist a patient to have the means to be well- informed in what they hope for.

4.2 Examining Hope.

There have been many conceptions of hope and I will refer to a number of these in building the core of my account of hope for the development of an argument that some accounts of hope can potentially result in doctors' and patients' obligations towards each other being too weak, while other accounts of hope can potentially result in doctors' and patients' obligations towards each other being too strong.

Both doctors and patients, ought to be motivated by the patient's interests, and in addition ought to at times consider how what is hoped for might impact others. This is because a patients' interests might be linked in different ways to the interests of others in their community. As I will explain, certain conceptions of hope might lead to the formulation of different objects of hope that might be more or less prudent for a patient and have more or less impact on others around a patient. Patients and doctors ought to be mindful of what conception of hope they ought to apply in a professional clinical relationship as some conceptions of hope can lead to expectations of others that ought not to be imposed on them.

I will briefly discuss a few accounts of what hope may be¹⁶¹, and I will then use parts of these ideas to outline the notion of hope that I will use in this thesis to argue that some notions of hope ought not to be used in ethical health care I will argue that health care based on well-grounded beliefs rather than fantasy, allows for more co-deliberation between the doctor and patient, whereas hope that is based on fantasy can lead to a patient having a commitment to follow a certain fantasy or faith to the detriment of other considerations that the patient would normally consider important.

I will first present what seems to be a "probabilistic based" definition of hope that I will argue is incomplete as it fails recognise other aspects of accounts of hope, however it is useful as (relevant to health care) it highlights that "realistic" hope rests in part on an assessment of probabilities by the person who is forming that hope.

Snyder is a prominent psychologist whose book and articles on hope feature in many discussions by those who present a highly cognitive account of hope, which emphasises an agent's construals that these theorists take to be involved in hope .

¹⁶¹ I say "briefly" as it is not my intention to focus this the chapter exclusively on an account of hope, rather I intend to debate how hope may be misunderstood or used in ways that I will argue have adverse ethical implications.

This account can be contrasted with more cognitive- affective accounts of hope that allow scope for what are often taken as the emotional aspects of hope to have more prominence than is recognised by the former accounts. Snyder writes, in one of his initial formulations of what hope is, that. "Hope is the sum of [what is] perceived [by the agent as their] capabilities to produce routes to desired goals, along with their perceived motivation to use those routes" (C.R Snyder, 2000, p. 8). Snyder also states his later published formulation of hope where he claims that. "A second hope definition described it as "a cognitive set that is based on a reciprocally-derived sense of successful agency (goal-directed determination) and pathways (planning to meet goals)" (C.R Snyder, 2000, p. 8)

Snyder's accounts of hope both place hope as a measure of what one believes to be one's ability to control one's destiny and to find ways to overcome hurdles. These accounts also see hope as a "cognitive set" which suggests that Snyder believes hope is solely a matter of cognition¹⁶². In the account of hope that I argue for below, I borrow from Snyder the notion that hope includes an evaluative judgement of ones' capabilities of attaining some goal that one is motivated to strive for. While in the account of hope that I will defend, the ways to find grounds for hope may be more or less emotional, the evaluative judgement aspect of Snyder's "adding up" of perceived capabilities suggests that hope also contains deliberative qualities that are particularly relevant to health care decision making that I have argued often ought to be deliberative and co-deliberative. Snyder claims that hope involves people judging that they have agency, "belief in one's capacity to initiate and sustain actions" (C. R. Snyder et al., 1996, p. 321), and a perception that a pathway may be found through

¹⁶² In the APA dictionary of philosophy, a cognitive set is explained as "the predetermined way an individual construes a situation, which is based on a group of concepts, related to the self and other things, that determines an individual's view of the world and influences his or her behaviour." <https://dictionary.apa.org/cognitive-set>

difficulty to reach certain goals or to avert certain outcomes (Lear, 2008; McMillan, Walker, & Hope, 2014).

While differing types of hope involve differing levels of probabilistic assessment of what can be hoped for, it has been highlighted for centuries that the object of hope is not the same as hope itself. I will later argue that understanding this difference has important ethical implications in health care. Some objects of hope involve a form of anticipation towards a state of affairs, whereas other objects of hope relate to probabilistic assessments about the future. St. Thomas Aquinas stated that the object of hope is "what is agreeable, future, arduous and possible of attainment" (Godfrey, 1987, p. 34).

I will now argue hope is most plausibly understood as an emotion,¹⁶³ rather than a "cognitive set" as evidenced by the level of passion that hope may evoke in an individual, and also by the feeling of despair that may be strong when hope is fading, as is seen in some forms of depression (Beck, Weissman, Lester, & Trexler, 1974). For the purposes of this work, I defend an account of hope which holds that hope is,

An emotion of an agent, informed by reason/s directed at what is agreeable, future,

¹⁶³ Before coming to the definition of hope I will refer to for the purpose of this thesis, I will briefly discuss the nature of emotion. Emotions are hard to define and indeed emotions may be on a spectrum between seemingly more or less reasoned or deliberative process. Generally, emotions are said to contain elements of conscious and visceral feelings *and* deliberative processes that lead to a behaviour. The philosopher Aaron Ben – Ze'Ev argues that emotions are a *mode* (Goldie, 2009, p. 41). The mode of affective state I use in attempting philosophical writing differs from the mode of consciousness I am in when I play a late Beethoven string quartet, or from the mode I am in when forming emotional links with another person. For the purpose of this discussion, emotions are neither fully deliberated upon from reasons nor fully derived from feelings but, in variable amounts, a derivation of the two. Emotions are often, but not always, salience setting or motivating for an agent. Though reason and deliberation do have a role in the origin of emotions, by considering themselves influenced by emotions an agent allows for factors that may impair what they consider their usual normative standard of deliberation. Since the stoics and enlightenment philosophers have argued that emotions lead us to peril, as indeed emotions can, so too reason can beguile.us. Plausibly it can be held that as emotions are in part derived from reasons so to reasons may be in part derived from emotions.

arduous and is foreseen by the agent as possible of attainment.

I argue that all forms of hope, from that of hope in spirituality or hope in health care, necessarily require some emotion *and* reason/s (e.g., cognition). In using the word “reason” I use it in a minimalist sense to refer to even cognitions that are poorly grounded or not informed by some standard of “reason” that patients and health practitioners might agree ought to apply in health care. In a broad account of hope, a person might hope for objects of hope that they believe are possible to attain, but in fact are impossible to attain. A central claim of this chapter is that though hope is an emotion, patients and doctors ought to not reject outright consideration of deliberative processes that would commonly be applied by them to other important decisions when they come to decide upon what to hope in or hope for in most healthcare. Nor ought patients and practitioners to formulate what they hope for in health care solely on affective grounds without considering practitioner’s advice that they reasonably ought to attend to. I will argue that not only may harm to patients ensue if the nature, limitations, and importance of different types of hope are conflated by the doctor or by the patient in health care but also by conflating those aspects of hope in such ways, doctors and patients might develop unreasonable expectations of one another.¹⁶⁴ Over the next pages, I examine six aspects of hope that are central to this work’s analysis of this concept, as these apply to health care ethics that is based on fallibilist principles used to determine what patient and doctor owe each other. These aspects of hope are as follows:

A. Hope is integral to the human individual.

¹⁶⁴ By “unreasonable” here, I am referring to what either person agrees they can tolerate of each other based on agreed social norms of what is expected a doctor ought to do for a patient and what a patient can expect from a doctor (see also section 3.6)

- B. Fallibilism, hope and health care.
- C. Hope necessitates acknowledgement of change and a person's future.
- D. The object of hope is uncertain and arduous.
- E. Objects of hope in health care generally ought to be well grounded and not based on false beliefs. We ought to be wary of poorly grounded and "false hope" in health care.
- F. Hope is driven at least in part, by our desire to avert despair and as despair can have associations with poor health, at times doctors ought to try assist a patient to avert despair.

I will now defend each of these claims:

- A. Hope is integral to the human individual.

Such a position is ancient., For example, "Dum spiro, spero", the Latin proverb translates roughly, "As long as I breathe I hope" (Mittleman, 2009, p. 24). I understand hope as an emotion that arises from our wondering minds, and fashions individual aspirations – a foundation of psychological wellbeing and psychological function. I believe that humans tend to be "hope addicts" with a disposition to imagine multiple developing hopes, and as one hope seems less likely to come to fruition or becomes reality, we then develop and strive towards meeting other hopes. Hope has motivational effects in the way that it necessitates a person to at least consider their future and thence have the option to try to steer their future. Alan Mittleman argues that we often have fallback positions of hope - that is, as one hope seems less real, we usually develop another (Mittleman, 2009, pp. 4-6) As Johnson put it;

'The natural flights of the human mind are not from pleasure to pleasure, but from

hope to hope' (Johnson, 1890, p. 34).

Further Plato in "The Philebus" (Plato, 1975) expresses this discontent of multiple hopes in his discourse on emotions when he says that.

... "all men are in turmoil with countless hopes" (40 a).

It is conceivable that our minds are inevitably in a state of discontent (Freud & Sigmund Freud, 1962) and, that this discontent is a catalyst to an endless cycle of generating new hopes until we die. This discontent is linked to the arduous character of hope. It is almost as if the human condition contains a "hope obsession" where, as our circumstances change and as we mature and alter our ideas, or as possibilities expand or contract, so too our hopes expand or contract to fit the more limited choices that we arrive at.¹⁶⁵

To give context to the thesis title, due to hope's importance to a patient, a doctor and patient ought to be particularly attentive to what the patient hopes for as relevant to their health. Additionally, we reasonably expect that the ethical doctors' hopes to be a good carer are in part aimed at assisting the patient to achieve what they hope for as relevant their health. Assuming that a doctor sees it as their professional obligation to care for their patients and what they hope for, caring for what a patient hopes for may be *part* of what a doctor sees as constituting their identity as a doctor. I will not give a detailed account of identity at this juncture but at least one author (Appiah, 2016) has argued a person's sense of identity might plausibly be held to be derived from factors such as race, religion, relationships and a person's work. If a doctor finds it personally important to be good at their job, and believes that part of doing a good

¹⁶⁵ This notion fits in well with an account of health care ; where health care is concerned with aiding people to adapt to change as illness brings alterations in how patients feel control of their lives compared to their previous "healthy state" (Carel, 2008). It seems reasonable to claim that a function of hope in health care is to facilitate our attempt to bring order to us from the world around us over which we have limited control. A feeling of lack of control can come as we unexpectedly fall ill, and so hope may be important for a patient to feel a sense of control.

job is caring about what a patient hopes for in seeking that doctor's care, then it ought to be important to the doctor to care about not just what the patient hopes for but how they come to form their hopes. Patients might reasonably be expected to attribute certain virtuous characteristics to their doctors, such as diligence manifested by taking pride in doing a good job. A decisionally capable patient might also reasonably be expected to appreciate that what the patient hopes for also might personally impact on what their doctor hopes for, as the patient might reasonably hope that their doctor should be professionally invested in the patient's health hopes. In the special patient doctor relationship of the I.D.D.P.R., a patient's objects of hope might place burdens on others who feel an obligation to care for not only a patient's best interests, but also for what the patient hopes for. What a patient hopes for might impact on doctors and other carers in a way that the patient ought to recognize and not ignore, particularly if their doctor or other carer expresses concern about how or what a patient hopes for in the patient's health care.

In short, particularly if there is a special relationship such as the I.D.D.P.R, there ought to be a degree of reciprocity in caring about what each other hopes for. Either person ought to at least attend to the others' concerns about the grounds for an object of health care hope as while assuredly an object of hope might be important for the patient's sense of identity, the patient ought to acknowledge that rejecting their doctor's concerns about what they hope for in health care might have a personal impact upon their doctor.

B. Fallibilism, hope and healthcare.

I suggest that unless very depressed, many other people are "hope addicts" with

multiple more or less important hopes all rising and falling at once. An agent in an attempt to avert despair (Marcel, 2009)¹⁶⁶ has various hopes that they are striving for, and as some hopes become less viable, then other hopes become more worth striving for. A person with many hopes that they can “fall back upon” thus embraces fallibilism as they accept that any one hope might become less plausible.

Acknowledging fallibilism gives a person the chance to “not put all their hopes in one basket” and thus other hopes are given a chance to form as occurrent hopes are pursued. Whereas if one has a dogmatically held view of the future then one might be more bound to a path to despair if that dogma proves wrong, as there is no foreseeable alternative in a dogmatic system of finding objects of hope. As argued, hope is not the same as belief, as beliefs are part of what form objects of hope but hope also involves an affective component. However, the same epistemic processes that lead to beliefs might be present as one forms objects of hope, so people with fixed dogmatically held beliefs may have difficulties in forming “fall back hopes”,¹⁶⁷ if they can only have one or a limited number of dogmatically held beliefs.¹⁶⁸ The variety of hopes that a dogmatist may hope for might be restricted as compared to a fallibilist as the former’s dogmatically held belief leads them to not consider alternatives and potential obstacles and stifles their imagination for alternative futures.

To illustrate this in health care, consider the case of a patient who accepts what is plausibly foreseeably believed to be futile therapy to treat what would have been a curable cancer (for example many testicle cancers) and is in a position of reflecting on

¹⁶⁶ See section F below

¹⁶⁷ That is, hopes they may become more important to them as the objects of hope they have been pursuing, seem to them less possible of attainment.

¹⁶⁸ For example, if a parent has a very dogmatically held belief that their only hope to “cure” their baby’s colic is to subject their baby to a series of Gonstead chiropractor “adjustments”, it may be hard for the parent to even consider alternatives objects of hope, for example based upon the belief that their baby’s colic is not harmful and will go away with time.

their decision on their death bed, when they might otherwise have lived. If they had chosen to believe a faith healer and accepted an ill -founded promise of cure, then as they die they might recognize that the dogma they chose to believe was epistemically unwarranted and misguided. As they continued with a futile therapy, the patient and the health practitioner might have continued in self-deception (possibly due to biases¹⁶⁹) as more evidence accumulated of the patient's demise. If a fallibilist path had been taken, then futile therapy might also have occurred but at least there was the possibility to reconsider the situation rather than be locked in by dogma to a certain path. That is; fallibilism gives the patient more possibilities should they choose to consider them, whereas dogma knows but one truth that in time may prove wrong, and a patient may regret not having developed fall-back plans.

A propensity to make “fall-back plans” and the desire not to put “all one’s eggs in one basket” can be seen in many other areas of human decision making (-other than in health care) where the agent seeks to ameliorate their uncertainty in evidence that is used in making a choice. The finance and insurance sector encourage a diversified investment portfolio, and people pay for insurance as they allow for the certainty of their own uncertainty and the uncertainty as to which investment will perform the best. Students might seek out diversified career paths but often have “preference lists” and notions of alternative career paths should doors to job options close. Most engineering systems have built in tolerances and “built in redundancy” or monitoring systems as so many things about our environment and ourselves we assume may be fallible. An attitude of fallibilism seems to be linked to our own uncertainty that machines and systems will not always function as we expect. The “Swiss Cheese model” of James Reason has fallibilism at its core. As Reason puts it, “The basic premise in the system

¹⁶⁹ As per section 5.8

approach is that humans are fallible and errors are to be expected, even in the best organisations” (Reason, 2000, p. 768). Reason postulated that the best management systems have multilayered levels of safety systems that are assumed to have holes in them, waiting to be found. In this model, the most effective system is based on an attitude of fallibilism, and so people develop systems to look for such holes.¹⁷⁰ Most of the time the systems avert accidents but at times “all the holes line up” as if in a block of Swiss cheese where “holes in many layers momentarily line up to permit a trajectory of accident opportunity”(Reason, 2000, p. 769) i.e. an adverse event leads to a series of effects, which then results in a catastrophic outcome. This concept was first applied to aviation, but health care systems are analogous in that there may be failures due to “System and Person approaches” discussed by James Reason. A recent such case in medicine, where multiple processes and factors all happened concurrently and caused a medical disaster, occurred in the strained British health service, where Dr Bawa-Garba (Samanta & Samanta, 2019) was initially deregistered from practice as a doctor, due to many “holes” in a failing system lining up, to result in suboptimal care before a boy’s death.¹⁷¹ Though the medical regulators initially placed blame on one doctor, subsequently it was shown that, as with aviation disasters, multiple causes were behind an effect. Awareness of fallibilism gives people the opportunity to seek and find possible impediments to what they hope for

¹⁷⁰ Or the holes are known but other layers of systems are put in place in an attempt to mitigate the weakness, for example human or metal fatigue.

¹⁷¹ Part of the reason for widespread coverage of international doctor’s outrage in response this case, was that the open system of clinical audit used by doctors to learn from errors, was initially used by the British medical council to wrongly claim to show evidence of the guilt of the individual doctor, for what was a health system failure. That is, doctors were outraged that their systems set up to bring transparency into the health system so that those who use processes of E.B.M. can learn from errors, was used to lay blame one person for what was a complex chain of causal failures.

C. Hope necessitates acknowledgement of change and a person's future.

It is important for my overall argument that I demonstrate that hope implies recognition of change or of the possibility of change.¹⁷² If a patient refuses to recognise the possibility for change and the importance of a fallibilist approach by refusing to at least consider alternative conceptions of the future, the patient might curtail alternative hopes. However, fallibilism allows for preparation for change and allows for alternative conceptions of what a person might become in the future in a way that a dogmatic epistemology might negate. Hope is in a sense a promise about the future, but it might involve a false promise – we can be self-deceived, or deceived by others, thus altering our life plans. This deception may be derived from fallacious assumptions that inform the reasons that lead to our hopes and we may be deceived by our emotions that also change as our insights change (Pugmire, 2005).

Hope is inexorably linked with our conception of awareness of a future and the acceptance of "self" in a context of a timeline (Parfit, 1984). With awareness of a future self, a patient might have reasons to hope for their future and also for the interests of those they have special relationships with. Hope for something is, in part, to expect (at least in some sense) something to transpire.¹⁷³ Aquinas argues that hope is directed towards some imagined future. A key catalyst, of hope, is our appreciation that time changes us, and our surrounds. If we hope for something, we are conceptually required to recognize the possibility of change as opposed to dogmatically accepting that something infallibly will occur (even if we hope for maintaining the status quo). As

¹⁷² Even if a patient hopes for things to stay as they are, this implies acknowledging that change is possible, because, as later discussed, there is no point in hoping for that which is inevitable. If the status quo is certain, there is not much point in hoping for that which is certain.

¹⁷³ In brief, the nature of expectation I refer to is our imagination of what the future will be, be it negative or positive. Expectation pertains to what we think is more or less likely will occur, and our imagination can be informed by what we believe.

Plato put it, “everything is in a process of constant change.” in 43 a (Plato, 1975).

The ability to hope, and to imagine a future self, plausibly links hope to a sense of agency. To appreciate the notion of ourselves on a timeline is an aspect of having "agency" or an awareness of self as an ongoing personal identity, with the existence of some form of autonomy with certain "ground projects" (Scheffler, 1988; Williams, 1981). In this manner the previous discussion of identity can be seen as linked to the present discussion on awareness of self over time. Autonomy has many definitions that are widely debated but for the sake of brevity autonomy might be broadly understood to be a property of a competent agent, who self-rules and has rights in that they make certain voluntary choices. As Singer's discussion of personhood explains, John Locke defines a person as a, “thinking intelligent being that has reason and reflection and can consider itself as itself, the same thinking thing, in different times and places” (P. Singer, Singer, & Cambridge, 1993, p. 74).

Another contemporary author Michael Tooley writes on the subject of self in the context of rights; and defends a position that, “the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity” (Tooley, 1972, p. 44). Bernard Williams coined the term “ground projects” to describe the plans people form that are central to their autonomy. These ground projects suggest that we think of our future selves and hope for certain futures. Some ground projects have a role in imagining hurdles to what we hope for and function in assisting us to plan to find ways to overcome such hurdles. Departures from health can be seen to have the potential to significantly undermine what people hope for.

Patients may reasonably expect health practitioners to assist them in deliberating upon what future health hurdles might be and upon ways to overcome such future and

present hurdles. One important reason why a patient might seek a health practitioner's advice or assistance is to attempt to avert disappointment and to overcome obstacles to what they hope for with regards to the patient's future health. The patient's future hopes might properly pertain to short and long-term objects of health hopes. However, what the patient construes as short-term objects of hope might impact on what the patient hopes for in the longer term with respect to their health. For example, a carer might reasonably believe that an obese patient is attending to a short-term object of hope; to lose weight immediately by taking an amphetamine type drug (that only works while being taken and can have dangerous side effects) rather than by attending to the longer-term hope of slow sustained weight loss that will facilitate the achievement of many other longer term aims the patient has for their health. Such a patient ought to respect that their carer may try to persuade them to take actions that will promote, and not hinder, what the patient hopes for in their health in the longer term. In the context of the I.D.D.P.R., the ethical health practitioner ought not to always support a patient in their short-term health choice, for example to take amphetamines, even if it is important to the patient to fit into a certain wedding dress by next week. Fitting into the wedding dress might have many psychosocial benefits to the patient and fulfil a patient's long-term hope of being size 14 for their wedding. However, this object of hope might jeopardise an even longer-term object of hope, such as reaching a healthy weight well beyond marriage in order to be less at risk for four pregnancies. A patient might reasonably be asked to consider that what they hope for now might change and that what they hope for now might effect what they hope for in the future. It is reasonable to expect a patient to appreciate that their carer should care not only for

the patient's shorter-term hopes but also for their longer-term hopes.¹⁷⁴ At times carer and patient ought to co-deliberate on such types of hope. Having decided together upon what principles they cannot reasonably reject, for example that the doctor ought to (where possible), protect the patient from harm- such as a patient's acting on their desire to use amphetamines for weight loss- the patient ought to appreciate why the doctor seeks to provide the patient with differing perspective on amphetamines and at least consider what the doctor is saying.

It is important to differentiate human hopes from mere drives and desires.¹⁷⁵ At times a doctor ought not to support a patient in what they desire, because what the patient has a desire for may not be what the patient ultimately hopes for. This is because what a patient desires now, may not help the patient in what they hope for in the future. A patient who seeks a doctor's help to fulfill a current desire, while seemingly disregarding what they will likely hope for in the future ought to appreciate that their doctor may feel obliged to not assist them with a short-term desire. What the patient desires can change, as can what they hope for and the action they take in the present can alter their future health. Not only what a patient desires but what they hope for may be more or less important to the patient at different times in their life.

Joseph Godfrey highlights that there are different types of hopes, with some hopes of great importance to the person (Godfrey, 1987). Godfrey contrasts desires with hopes, and defines desires, among other things, as not themselves being hope, given that desires are aimed at the acquisition of something more immediate, whereas many

¹⁷⁴ A dogmatically held belief in a right to a principle of the importance of the freedom of choice for a current desire, could foreseeably be imprudent as it precludes a patient from considering alternative objects of hopes for their future. In rejecting fallibilism a patient might disregard carers who seek to share with them alternative possible grounds for genuine hope, where a patient's occurrent desires plausible offer less genuine grounds for hope.

¹⁷⁵ Another reason to highlight such a difference becomes relevant later, when I later compare a consumer's desire to purchase make up, with a patient's hope for effective care.

hope(s) pertain to at a longer term state of affairs. Though we desire what we hope for we may or may not always hope for what we desire. For example, a man may desire a woman sexually but not expect or hope to engage in sex with that woman, as to do so would damage many other features of his life. The object of sexual desire in this context, is not reasonably attainable or agreeable, though it may be arduous. A person may have many desires that will never be acted on partly because such desires might clash with their life plans. Robert Young (Young, 1986) argues for a plausible notion of “dispositional autonomy” whereby short term desires pertain to “occurrent autonomy” whereas longer term “life plans”¹⁷⁶ might be akin to longer term objects of hope, and may give meaning to a longitudinal sense of autonomy. In this manner, many hopes are linked to longitudinal autonomy by what is hoped for. Longitudinal autonomy I understand to refer to what a person believes that they have agency in relation to, as the same person over a period of time. It is important to my overall argument that a patient’s longitudinal autonomy ought not necessarily be trumped by their occurrent autonomy and freedom of choice for a present desire, as the longitudinal life plans of an agent might be at least as important for defining who they are as may their occurrent free choices.

Godfrey argues that there are “ultimate hopes” that relate to a person’s disposition or focus, and “fundamental hopes” that have a particular aim or target.¹⁷⁷ This discussion forms the basis of his book. For Godfrey, ultimate hopes are the high-level

¹⁷⁶ Perhaps akin to “ground projects”.

¹⁷⁷ For example, perhaps the ultimate hope for one who is aligned with the ideas of virtue ethics is to lead a virtuous life and to abide by virtuous principles as a virtuous person would. This is an example of an ultimate hope. A fundamental hope may also be important but be more specific. An example of a fundamental hope is, “I will study hard for my secondary school so that I may attend university and increase my chances of a good outcome in the job market”. A person’s entire purpose for living may not have to be revised, if s/he does not get into university and s/he becomes a tradesperson instead, as a person’s ultimate hope to be a virtuous person may not need to change if they are a plumber.

hopes that provide a person with reason(s) to live and define what they are aiming for in life, and "where they are going" with their lives. These ultimate hopes are analogous to "ground projects" (Scheffler, 1988; Williams, 1981). Ultimate hopes are part of what characterise a unique person and are said to be linked to the concept of identity; "hope is so closely tied to identity"(McMillan et al., 2014, p. 36). Religious hope seems to fit with ultimate hope, or perhaps a person with a strong sense of vocation can have a work objective or professional role as integral to an ultimate hope.¹⁷⁸ For Godfrey, fundamental hopes seem to relate more to daily functions, (such as getting to the bus on time) and ultimate hopes touch on broader states of affairs that a person is aiming for with their life.

The failure of fundamental hopes may be disappointing, however what is particularly relevant to health care is that failure of ultimate hopes may lead to despair, where the agent sees no reasons left to plan for a future. If hope is so linked to identity, agency and imagined future self, it is no wonder that a carer who challenges what a patient hopes for might be seen by a patient as disrespectful to that patient. A person might feel offended by one who seems to challenge a component of what they feel is their cherished hope, even where no offence is meant. For example, a patient might feel offended that their doctor would attempt to thwart them from taking amphetamines as they really desire to get to size 14 for their wedding. However, if both doctor and patient operate in a setting of a fallibilist relationship of respectful co-deliberation, the patient might appreciate the doctor's questioning of the patient's grounds for what they believe is their current "fundamental hope", that may not serve their "ultimate hope". Furthermore, it might be that the patient objective to become size 14 is actually a

¹⁷⁸ In this way (some) doctors and priests may have similarities, in their professional role being a personal "ultimate hope" linked to a sense of vocation in their work.

desire, not a hope. If such questioning of a health-related desire or hope is done in a sensitive respectful manner it need not be viewed as an attack on the patient's agency¹⁷⁹ but as a matter of the health practitioner showing consideration of the possibly fallible grounds for what the patient currently hopes for. In a fallibilist model of the I.D.D.P.R. that recognises the possibility of change, suggesting that a patient might wish to consider change in something valuable that they hope (or desire) for can be seen as respectful, rather than perceived as an attack on another person.

D. The object of hope is uncertain and arduous.

A fourth aspect of hope that I consider important is the point made by Aquinas that a part of hope is the need for the person who forms hope, to believe that there is adversity or difficulty in the process of attainment of the object of hope. For Aquina, "What distinguished hope from desire is the character of hope's object as an arduous thing, attainable with difficulty" (Miner, 2009, p. 217). I now argue that without uncertainty about whether there will be an obstacle to the object of hope (or whether one will be able to overcome such an obstacle), there is no reason to hope. For example, if I am an elite mountaineer, walking up a steep hill by lunch time may not be something I hope for as I feel I know I will do it with minimal effort, where as an unfit person recovering from illness may have the hill walk as an object of hope that they wish to strive for. Something that is construed by a person as being inevitable may well be "reasonably foreseen as attainable" but it is hardly worth hoping for, as the person is certain that they will attain it. We may contrast the adversity involved in more

¹⁷⁹ In my clinical role this has occurred when I have attempted to engage people in discussing vaccinations, mask wearing in the Covid-19 pandemic, deferring effective chemotherapy etc.

well-grounded hope¹⁸⁰ with faith or a fantasy that therapy will provide a certain cure. Let us consider the case of a parishioner attending a Pentecostal healing service hoping to cure an ailment. The parishioner shares a belief with the pastor that “all you need is to have faith” and cure will come. Cure might come through such a process and a patient can genuinely hope for cure based on their belief that their strength of spiritual faith can bring cure.

However, if the parishioner’s faith is not at all arduous to attain or the cure is believed to be inevitable if only the parishioner “just has faith” the kind of emotion that the parishioner has, seems less responsive to evidence. Such faith may be problematic for others who might seek to bring into co-deliberation the fact that what is sought by the parishioner significantly impacts certain others¹⁸¹. Such an emotion might be more appropriately construed as optimism (that is discussed in the next section) rather than as hope.

It could seem that hope can pass from one person to another in a manner that is not arduous but in fact feels joyous. For example, if we consider the “healing services” of some Pentecostal churches, the environment of expectation of cure and group dynamics may facilitate in “believers” an “emotional contagion”¹⁸² effect whereby the perceived strength of hope of the healer, gives the parishioner strong emotional grounds to feel hope in the pastor’s healing powers. Indeed, the persuasive power of the patient’s faith over the patient’s usual decision-making process, and what the patient feels that they owe to the pastor or the faith, can influence what a patient considers to be grounds for their hope in relation to their health care. However, in such cases it seems that it is not hope itself that is given or mysteriously transferred from

¹⁸⁰ By “well-grounded hope”, I mean hope that has grounds based on reasons and evidence we can agree are good evidence for that situation or belief. At times well-grounded can also refer to what is based in reality

¹⁸¹ This might be particularly where there are effective treatments that the parishioner refuses to acknowledge.

¹⁸² For a definition see near start of section 3.5

the pastor to the parishioner here, but that the feelings which are triggered in the parishioner by the priest that become grounds for the parishioner hoping for a particular health outcome (which may or may not be well-founded).¹⁸³

Faith might be more or less arduous to attain and maintain, and a person might have strong faith that is not arduous but is seen as something inevitable to them. If the parishioner claims that their firmly held dogmatic faith “comes naturally” or “just came to them” and is firm faith that cannot be shaken or challenged, then such a basis for hope seems not to be arduous. Whereas if their faith is hard to maintain as they acknowledge that they could doubt some aspect of their faith, then such faith might be arduous as it requires appraisal to be attained and possibly to maintain. Faith may or may not be arduous to attain however hope requires a level of doubt and effort to attain.

To dispute the uncertainty about our future may be one of the criticisms of writers such as (younger) Nietzsche who in his rather nihilistic philosophy considered hope not a virtue but a vice (Godfrey, 1987, p. 1). Nietzsche wrote that hope is, “the worst of all evils because it prolongs the torments of man” (Nietzsche, 1996 p160). The idea that hope is self-delusion is captured by Tadeusz Borowski, who wrote from his Auschwitz experience. “We were never taught to rid ourselves of hope, and that is why we are dying in the gas chambers” (Godfrey, 1987, p. 1). I understand Borowski to be suggesting that the camp inmates hoped for rescue for too long, and thus did not consider alternatives such as escape, rebellion etc. What the inmates hoped for was, “a world that would be different. For a better world to come when all this is over”

¹⁸³ I claim that differing types of hope may be infectious like other emotions. I further argue that the emotion of hope is a more reasoned in its formation than for example an emotion like anger. I argue this because hope is about overcoming obstacles and finding ways to prevail and so the “hoper” must appraise possible ways to achieve what they hope for. While anger conceptually can directly pass from one person to another, hope is a forward- looking emotion and unlike emotions such as anger, hope in the area of health care requires more deliberation than other emotions.

(Borowski, 1976, p. 121). But as I will now argue, for the Auschwitz condemned it is not clear that their hope betrayed them. It is a misconstrual of hope, to view hope as naive optimism that promulgates inaction or necessarily leads people to struggle for objects of hope that are based on self-deception. Inmates made a well-intentioned choice with the best knowledge available to them at the time, with the emotional conditions at that time driving those choices. In the end what many hoped for was in vain. It is significant that prisoners died despite their hopes not because of them, though Borowski is claiming the opposite.

Paradoxically, it was precisely the uncertainty of the prisoner's fate that was a source of *possible* grounds for hope, and capitulation of all hope was based on a false belief that there was no chance any one individual would survive Auschwitz.¹⁸⁴ Nietzsche's nihilistic vision for the future was perhaps arrogant in being so certain that the future is always bleak, so a person ought to give up trying to hope now as there was no point.

In contrast while many health treatments are highly effective, this does not mean that a "good" clinical outcome is inevitable. In a fallibilist ideal deliberative model of the doctor-patient relationship, as no treatment is inevitably effective, dialogue ought to occur for both parties to consider other pathways for hope if a complication arises from what was considered to be an effective therapy. Whereas if successful treatment seemed to be inevitable, it would seem hardly worth the carer and patient considering alternative sources of hope, let alone hoping for a therapy that that they "know will

¹⁸⁴ Nietzsche subsequently evolves his view and argues that though hope is in his view deceptive, hope helps us to carry on living in illusion. Nietzsche compares hope to a "rainbow" and argues hope is transfigurative and can make one live life better. Nietzsche writes, "Let your love to life be love to your highest hope; and let your highest hope be the highest thought of life!" (Nietzsche, 2006) chapter ten, War and warriors. The Auschwitz prisoners in retrospect were generally "hoping in vain" that they would survive, but some inmates did survive so their object of hope though remarkably improbable, was possible. Such an "ultimate hope" to survive Auschwitz, plausibly gave their lives some dignity and meaning where hope was all but exterminated. Though the remote hope of leaving Auschwitz didn't save most from death, it likely saved them from nihilistic despair. Foreseeably futile objects of hope can be delusion promoting, however the *realistic chance* of survival for some inmates, meant hope to get out of Auschwitz via the gate rather than the crematorium chimney, was genuine hope for all, though not realisable hope for all the inmates.

work". To desire to use amphetamines to rapidly lose weight may be a certain way for a patient to achieve weight loss in the short term, but this is hardly a form of hope in the way that what is aimed for seems to the patient to be certain, and not arduous. The patient might feel disrespected by the doctor seeming to thwart what they desire, how-ever though doctors ought to help a patients with co-deliberation about what they hope for in their health, this might not apply to all of what a patient hopes for, nor to all of what patient desires.

E. Objects of hope in health care generally ought to be well grounded and not based on false beliefs. We ought to be wary of poorly grounded and "false hope" in health care.

"False hope", and poorly grounded hope as understood in the context of ethical health care, might not get the autonomous agent to their chosen destination and might be misleading. False hope is properly understood to be one kind of false emotion in part derived from the false feeling of the type that Plato described that I will discuss in a few pages. I argue below that patients and ethical practitioners ought not to base their hopes for a lifesaving therapy exclusively on such an emotion, even if the therapy turns out to be effective. Laurence McCullough summarises what might be widely believed by doctors to be "false hope". He claims that a definition of hope is;

"HOPE. A concept with two components: (1) the desire for a future state of affairs (2) that has a probability greater than 0 and less than 1. If the probability of a future state of affairs is 1, one should expect it to occur. If the probability of a future state of affairs is 0, the desire for it becomes a "false hope." (McCullough, 2018, pp. 156-157).

However, McCullough's account of hope seems to be overly cognitive, thereby

neglecting the affective dimension of hope. Such an account of hope and false hope also suggests that “false hope” might be commonly interpreted by doctors¹⁸⁵ to mean that such hope is not genuine hope as the object of hoped for state of affairs has 0% probability of arising. However, such hope *can* be claimed to be indeed genuine hope as hope is an emotion perceived as such by a person, no matter how improbable the grounds for such hope are thought to be. So called “false hope” in this context is I believe more precisely termed “misguided or poorly grounded hope”. Such hope may be based on epistemically unwarranted¹⁸⁶ beliefs or on processes of logic that a patient would not normally use. Informed, misguided and “superman hope” are all genuine hopes, but carers and patients ought to be attentive to which type of hope is epistemically warranted *and* morally justified in differing clinical settings. “Superman hope” is not “false hope” but is a unique kind of hope where the object of hope is impossible to achieve. Though superman hope is impossible to achieve, it is still possible to have a genuine emotion of hope to be superman. A person might believe in highly incredible fantasies and cite as evidence claims which are (and are broadly believed by their community to be) poorly grounded or epistemically unwarranted. Any hope I have to become superman is on McCullough’s account of hope “false hope” however it may nonetheless be “genuine hope” in the phenomenological sense in that I *feel*, such hope. However, the object of such hope is based on an epistemically unwarranted and false belief that it is possible for me to become superman.

I do not argue that false hope refers to cases where the object of hope that is not realised. I reiterate, such hope might have been genuine hope, in the sense that a patient could feel hope, however that hope was misguided. At least in a lottery there

¹⁸⁵ McCullough is writing in the context of doctors.

¹⁸⁶ See section 2.5.3 on credence.

is a very remote chance that one's hope to win might be realised, however in choosing a novel form of faith healing, never tried before for one's testicular cancer, there is even less evidence to base an object of hope on than there is in a lottery. Hope involves both affective and cognitive processes and some form of cognitive appraisal is particularly important in high stakes health care decisions. As an example of why in health care patients and doctors epistemically ought to attend to the nature of their objects of hope, Dr. Jerome Groopman in *The Anatomy of Hope* (Groopman, 2004), claims that patients ought to avoid what he calls "false hope" (or, what is more accurately called "epistemically unwarranted or ill-founded hope") as such hope impairs one of what authors (Groopman, 2004; C.R Snyder, 2000) argue to be hope's major functions- to find "realistic" ways around obstacles in the patient's quest to overcome adversity. "False hope doesn't recognise the risks and dangers that true hope does...False hope can lead to intemperate choices and flawed decision making." (Groopman, 2004, p. 198). True hope (by which Groopman seems to mean epistemically warranted hope), "takes into account the real threats that exist and seeks to navigate the best path around them" (Groopman, 2004, p. 198). Groopman further develops the idea that in hope's genesis one needs cognition,

"Hope is not blind like optimism and does not cast a veil over perception and thought. Unbridled fear by contrast, overwhelms hope, blocking out cognition and other feelings" (Groopman, 2004, p. 199). For Groopman, to a point, hope is responsive to cognition, but emotions may overwhelm hope and take over, removing the cognitive basis of hope in some cases. If a patient and doctor reject fallibilism, they can have reduced recourse to find justifiable reasons for each other (chapter one) and it might be difficult for the patient and doctor to decide what they owe each other, or loved ones, (chapter two) and imprudent for a patient if their misguided hope blinds them to

possibilities for well-grounded hope. If emotions that are supported by less transparent or infallibilist reasons dominate dialogue, it might be harder for a patient and doctor to come to agreement as to what a patient can or ought to hope for. I argued that all hope is an emotion tempered by cognitive appraisal of evidence that the agent may discuss with others, but I do not support the idea that hope is irrational or false unless exactly matched with the probabilities of a benefit. Particularly in the context of health care hope is not merely about just emotion. In health care hope morally requires some grounding in reason (even if mere cognitions) to work out what hopes have some (even if a small) probability of success in the context of a co-deliberative practitioner-patient relationship where the doctor and patient believe it is important to show respect for one another by enacting what they have determined that they owe each other.

What we hope for can affect others and what they owe us. For example, I might hope for a long and healthy life, but my children may feel obliged to care for me in my old age. I may contract a terminal cancer and hope to die at home, and this will likely affect what my loved ones feel that they owe to me when I am frail. If our fantasy provides us reasons to hope for things that would require us to unduly burden or harm others, we then ought to either keep the hope private, or not expect others to become involved in such hope that places an unfair burden on others. A patient or carer might hope for a therapy or health outcome that unfairly imposes on others as it violates the carer's own personal integrity or it is a major inconvenience for the carer to support what the patient hopes for. In such cases, if the ideal deliberative model based upon agreement of what is owed to each other is the basis of the relationship, the doctor and patient may debate the grounds of hope and determine in consultation with the other person

what is reasonable¹⁸⁷ to expect of the other person.

I now develop a case that genuine hope may be more or less well grounded in reality; with some hopes being foreseen by the agent as more based on more well-grounded or possible objects of hope and other hopes being based more on a fantasy. We accept that fantasy may or may not come true and in some situations we do not "get our hopes up" with dreams.¹⁸⁸ For example, reasoning tells us that I have zero % chance of becoming superman. To desire to become superman is fantasy, and so this is not a possible grounding for hope where other hopes may be more plausible to me and less fanciful. It is important to examine what may occur if we "choose to follow our dreams"¹⁸⁹ and act on a fantasy. I have not denied that some hopes based on fantasy might come true. However, to form an object of hope that is based on fantasy (such as to become Superman as, compared to a fantasy that is not as farfetched) we must acknowledge that just as with objects of hope that are better grounded, our efforts might not get us to where we want. However, if the object of hope is based on a fantasy that certain others do not share, we may find it difficult to justify the grounds for our object of hope to those who we feel we owe an explanation to because what we hope for involves them. In following what I am calling a fantasy we manifest a high level of scepticism in the usual norms of logic and reject accepted systems of evidence, if that

¹⁸⁷ The word "reasonable" appears throughout this thesis and I use the word reasonable in this context to describe a process of using some form of "Reason", with attendance to normative standards of logic and appraisal of the value of evidence in a deliberative process. I also use the word reason to mean "not excessive" again beyond certain norms. The term reasonable I also apply to people who use normative agreed processes of logic and co-deliberation. Further discussion in the area is covered in section 3.6

¹⁸⁸ I have not space in this thesis to give adequate account of dreams. Though dreams conceptually may be based in reason and reality and may assist us find reason, or become reality, I accept my dreams allow my mind freedom to go to fantastic places remote from current reality. In dreams my mind may fly and not affect others if I keep my dreams private, whereas reason allows me to fit in with others and live in the real world.

¹⁸⁹ I put "choose to follow our dreams" in italics as there might be debate as to if is conceptually possible to make autonomous choices by following, to what degree I am unsure, dreams that might be for example drug induced, or outside of our control due to other factors. I suggest that it is plausible dreams might arise without us having opportunity to appraise them or even be aware of them. We might not appreciate how dreams influence us and dreams might influence in ways we might seek to avert if they were open to us to cognitively appraise.

fantasy (that is as impossible as becoming superman) is set as my grounds for an "ultimate hope".

If one chooses to treat one's cancer with a psychic healer as "one really feels like it", and one rejects the need to look at evidence other than one's own intuition¹⁹⁰ that is based on a fantasy; one's logic may be justifiably critiqued as a limited or atypical type of logic that would not usually be applied. Furthermore, one would not usually cross the road, ignoring one's senses, based only on an intuition derived from a fantasy of being Superman. In crossing the road, we usually believe it prudent to use certain cognitive processes to appraise our perceptions of what we sense from the external world. If our objective is to get across the road, we ought to acknowledge that we usually attend to factors other than our fantasy. We might have an ultimate hope to be superman, however we will not reach that ultimate hope if we do not attend to our sense and use our cognitions to fulfil a fundamental hope of crossing the road safely.

To ethically claim to be involved in providing patients with well-founded grounds for hope, it is imperative for a practitioner to obtain the best and most relevant information that they can, in an attempt to predict the efficacy of a treatment. Though a patient or doctor might like or trust a fantasy (more so than what E.B.M. processes rank as salient evidence and the need to co-deliberate with each other), fantasy might prevent patients and doctors from appreciating what are effective therapies and might influence them to hope for the fantasy rather than for a better-grounded object of hope. Without recourse to some level of cognition, simply following a fantasy might harm a patient from overcoming an obstacle to their health, that might be as dangerous as a person crossing a road while believing that they are superman. Exclusively basing an

¹⁹⁰ A person may believe that in following their intuition they are expressing their freedom to think and believe what they want. Though intuition may be felt by a person to be free of deliberation and norms that other people have agreed to, it is not clear that intuition is anything other than based on habits of thought and attitudes that are highly normative, considered and rehearsed.

object of hope on a fantasy might also influence doctors and patients to attend less to what they owe each other and those who care for them.

There are distinct types of real or “genuine hope”. The differing types of hope I now discuss are phenomenologically real, and the objects of hope in health care rightfully pertain to beliefs that can be truth assessable. The object of any hope might be supported by more or less well founded, plausible beliefs. An object of hope in health care – such as a particular health outcome – can be assessed by the patient as being more or less reasonably attainable by the patient by examining whether the patient can plausibly achieve their health goal in the present or in the future.

In referring to “informed hope” in the context of ethical health care, I am referring to a form of hope where the grounds for hope are understood by the hoper, on the basis of relevant information, to be comprehensible by them, rather than to forms of hope which are based on something mystical or based solely on faith.¹⁹¹ Informed hope that may be facilitated in the schema of the three constructs is a type of hope a patient might feel when they are appraised of the evidence that seems credible for their situation and they substantially understand the grounds for what they hope for. I contrast this informed hope with to coming to hope in something with little cognitive effort, for example by feeling that the grounds for what they hope for is justified by something that they simply like. Hope of the type involved in spiritual beliefs or health beliefs may be like other emotions in that hope, like trust or even anger may be genuine, but might nevertheless be ill-informed. As beliefs may be ill-founded (Bortolotti, 2014) or deluded (Bortolotti, 2010) so too writers have argued that emotions may be more or less ill-founded or can instead be well founded (Pugmire, 2005). Hope may be ill-founded hope, in the way that a belief may be formed with

¹⁹¹ By mystical I mean unseen and unknowable. See chapter 5 for a discussion about the accounts of “faith”.

flawed evidence and hope may be misguided in the way that a belief is formed with defective norms of logic such as poor deduction or induction.

I argued that hope is an emotion and that objects of hope are based on beliefs that may be ill-founded, or well-founded. This complex area of philosophy of emotions has been debated for eons. In "*The Philebus*" by Plato, translated by Justin Gosling, a dialogue occurs between Socrates and Protrachus, whereby they debated the contentious possibility of "false pleasures", based on a paradigm feeling of pleasure (Plato, 1975).

In this dialogue Socrates claims that there might be something that he calls "false pleasure" (36c-41b). An emotion might be claimed to comprise feelings and cognitions (Plato, 1975). If this is the case, and hope is an emotion, then hope that is derived from false cognitions and/or feelings that are false (in the sense to be specified) might also be regarded as being false. In the following I provide a discussion that leads to what I construe is the proper meaning of false hope which is not the same as poorly grounded hope. Relevant to my thesis, false hope might not only be imprudent for a patient, but additionally false hope has the potential to bring unfair duties which are too onerous for those charged to care for what patient hopes for. The bulk of Plato's discussion on this subject relates to "anticipatory pleasure" and pleasure that is based on memories whereby it is claimed by the translator Gosling in his commentary that "mistake in this belief in some way infects the pleasure" (Plato, 1975, p. 50). That is, a person might realise that their belief was false, and this realisation might for example turn their pleasure to disgust that they could have been so wrong. Realisation of the error they made could turn an emotion (based on a false pleasure) from one emotion to another emotion. Similarly, a person might genuinely hope for a cure only to realise that the belief behind what they hoped for was ill founded and they might subsequently

feel hopeless and despair at missing an opportunity for a cure. I find this terminology of false pleasure or false hope to be problematic as at the time of having for example that hope, the hope is genuine. If mistakes can infect emotion rendering such an emotion false, only in retrospect can a person say that their hope was false. However, the following short quote from Plato's long dialogue on false feeling seems more compelling in developing an account of what seems to be more appropriately referred to as 'false feeling':

Socrates; Do you deny that some pleasures are false, and others true?

Protarchus; To be sure I do. **Socrates:** Would you say that no one ever seemed to rejoice and yet did not rejoice, or seemed to feel pain and yet did not feel pain, sleeping or waking, mad or lunatic? (Plato, 1975, p. 36 e).

Further examples of feelings being one thing and their opposite at the same time I consider are; the displeasure an endurance sports person experiences while at the same time experiencing pleasure in achieving a goal. Other examples might be the glutton who suffers displeasure while they have pleasure in eating, or the seemingly incongruous pleasure of some sadomasochist sexual practice. In standard epistemology something cannot be true and not true at the same time. It is illogical for a pleasure at the same time to be what it is as what it is not. Furthermore, arguably a person might feel pleasure when their senses deceive them, for example while under the influence of a drug, or as Plato says, "a lunatic" (Plato, 1975, p. 36 e)¹⁹². Plato provides examples of differing types of pleasure where displeasure and pleasure seem to co-exist, in more visceral ways such as the pleasure of scratching an itch to the

¹⁹² In a highly drug affected state or in a case of severe mental illness a person might not be able to appreciate what emotion is theirs or someone else's nor be aware of what they are feeling or believing. For example, in psychosis, people might not be sure what they believe is real. Nor might a psychotic person be sure if what they feel is real let alone if that feeling is their feeling or someone else's feeling. In such a state a person's emotion at any one time might be false, as what the psychotic person believes or feels may not be what *they* believe or feel.

point of pain (46a), or one might envisage more cognitive ways that involve predictions of the future such as the form of pleasure in malice or revenge (Frede, 1985).¹⁹³

“Genuine hope” can be based on fantasy or on what is considered mysterious in forms of hope that appropriately occur in matters of spirituality.¹⁹⁴ Hope based on an object of fantasy is not false, in the way that a pleasure that is at the same time unpleasant is (considered in Plato’s sense above to be) false. It is important for both carers and patients to understand the spectrum nature of hope - though a hope can be genuine, the genuineness of a particular hope does not yet indicate whether the object of that hope is properly in the spiritual domain or the health care domain. The phenomenological strength of a feeling of hope does not necessarily make that hope more or less well founded or what a patient or doctor ought to hope for clinical setting.

In the case of an object of a health hope being considered by a patient and carers as impossible to attain, there might be disagreement as to what the patient and carer believe is more or less possible. This might be not only because what is possible for one patient might not be for another but also because both patient and carer might not appreciate the unique circumstances of the patient in the same way, nor share the same beliefs about what is possible.

However- where there are effective treatments to offer unwarranted grounds for hope

¹⁹³ In a final example of false hope, an emotion can be false in the case of it being used by someone to manipulate another person’s emotions. A suitor might pretend they love someone in order to have some effect on the other person. Such love is false, as it is contrived and not what the suitor feels nor believes to be the case. In order to appear trustworthy, a doctor might pretend to care for a patient when they do not care for the patient. Such a doctor’s displayed “anger” in a patient’s therapeutic setback might be felt as real by the patient but not what the doctor really feels or believes. This deceptive doctor might give an impression to a patient that the doctor has great hope in a therapy. However, this impression of hope is ingenuine, false hope if the doctor does not believe in the credibility for the object of that hope and/or more importantly, the doctor does not feel any hope for the therapy helping the patient in their care.

¹⁹⁴ In a few pages in section 4.4 I discuss writings of Jonathan Lear who wrote a book based on the nineteenth century indigenous chief, Plenty Coupes. Though the grounds for the Chief’s hope, that became the hope of his nation, was a dream of a spiritual nature for him, the hope was realised, and the Sioux nation survived in a way initially unimaginable to the younger chief.

by offering a treatment that foreseeably has little or no chance of being effective, and to not clearly advertise it as such, is to give foreseeably false or weak evidence for grounds for hope, as in this aspect of hope the carer is misrepresenting the evident probabilities of alternative care. To encourage foreseeably misleading ¹⁹⁵ grounds for hope is always unethical, as it is not actually giving genuine grounds for hope if the chance of success is very low compared to an effective option, and if the probabilities are presented in a dishonest way. This is both misleading and deceptive. ¹⁹⁶

If it can be demonstrated that a patient has a type of “false hope” (such as a hope based on beliefs derived while a patient is delusional and drug affected) for a fanciful therapy where another therapy is clearly effective, then standard bioethical principles may be applied to claim that as the patient’s decision making capacity is impaired so carers are justified in attempting to dissuade a patient from their false hope. In such a case it seems less contentious to claim that hope in this health care setting ought to be grounded in the therapy that has strong evidence of success rather than placing a patients ill- founded, self-deceived delusions as the grounds for their “hope”.

A patient might hope for therapy based on false or ill -founded beliefs as each patient may give differing levels of credence to differing beliefs. However, a patient *ought* to acknowledge that those who care for them might give differing credence to a patient’s fanciful or false beliefs and might attach differing significance to the grounds upon which a patient bases their health hope. In cases of “high stakes” health decisions carers and patients ought to acknowledge that either party might give differing levels of credence to the view that a belief is false, fanciful or well grounded. In such cases, in a fallibilist model of the I.D.D.P.R., practitioners and patients owe it to each other to

¹⁹⁵ Or clearly weaker grounds for hope where there are readily available stronger grounds for hope.

¹⁹⁶ For example, Belle Gibson unethically offered false grounds for hope about so called anti-cancer diets and alternative therapies. See ; “The women who fooled the world” Belle Gibson's cancer con. Beau Donnelly, Nick Toscano publisher Scribe, Melbourne, 2017.

engage in co- deliberation to discuss why each of them ought to give more or less credence to more or less probable therapies and why one person might consider a grounds for hope to be false while the other appraises a belief to be true. However, debating the credibility of what is hoped for in a critical health choice is only part of the reason patient and doctors ought to attend to one another's beliefs. How the patient is placed in their social context and the implications for what they give credence¹⁹⁷ to with respect to their health also ought to be open for co-deliberation in the schema of the three constructs I argue for in thesis. Given the possible impacts of the doctor-patient special relationship on each other and those close to the patient such as their family, the practitioner and patient ought to at least consider why one or the other seeks to dissuade the other from following certain grounds for hope, or from being guided in health care decision making by genuinely false hope.

F. Hope is driven, at least in part, by our temptation to despair and as despair can have associations with poor health at times doctors ought to try assist a patient to avert despair.

In this section I develop a claim that despair has associations with departures from health. Such a link helps with delineating the rightful role of doctor and patient in determining what ought to be hoped for in a clinical situation. Despair is not the opposite of hope (as in a yin and yang binary oppositional model) but the desire to avert despair certainly is a motivating influence to hope for an alternative. Gabriel Marcel who writes extensively on the issue of despair and hope says,

...hope can only be seen as an active struggle against despair... it is not despair itself that lies at the centre of our condition, rather it is the temptation to despair....

¹⁹⁷ Credence was discussed in section 2.5.3

there strictly speaking can be no hope except where the temptation to avert despair exists (Godfrey, 1987, pp. 104-105).

In despair, there is, "a capitulation to yield before a certain fate laid down by our judgment to adopt the perspective of the worst" (Godfrey, 1987, p. 105) . According to Marcel, hope represents a non-capitulation to this complete internal destruction of self that despair may be. Hope thus seems to be a psychological defence against slipping into a state of self- destruction.¹⁹⁸

One of the aims of health care, is to avoid a patient's self- implosion, by nourishing informed hope that aims to avert despair by helping patients to find well-founded grounds for foreseeably possible hope. With this understanding, we can develop an attractive and plausible account of the role of hope, in the context of health care, that places hope as instrumental to the preservation of a person's integrity, rather than an end in itself. We may recall that I define hope as an emotion which includes a cognitive aspect. It would seem unlikely for an emotion itself to be a goal or an end, if we are talking about the sort of "ends" we think of when we think of ultimate hopes. Ultimate hope pertain to a state of affairs and often the goal of health care aims to assist such a state- that is a patient's best interests and integrity. There is empirical research that suggests hope is a useful resource for coping with stressful situations (Wienand, Rakic, Shaw, & Elger, 2018). Claims are made that a doctor is a,

"minister of hope and comfort to the sick"(Miller, 2012, p. 1616), however it seems more defensible to argue that while ministering well-grounded, more qualified hope to

¹⁹⁸ Psychologists attempt to avert this self- destruction that is linked to depression by a well-known counselling technique To borrow from the psychology sphere, a principle in a widely used counselling technique, Cognitive Behavioural Therapy (CBT), is to state that one has a choice to look at things in a positive way or a negative way and that is an individual's choice. The much-used example is that a person chooses to view a cup as half full or half empty. One may choose from any moment to look at the world and oneself in a negative or aggressive way and again this is an individual's choice as the individual determines how they feel, as in CBT "you feel how you think". Hope, then, is a choice to be disposed to look to the future and not accept the terrible consequences of giving into "negative thinking".

help a patient cope with adversity may be a role of doctors, a key aim of such endeavour is to avert a patient's despair.

Godfrey and Fitzgerald discuss how Marcel (Fitzgerald, 1979; Godfrey, 1987; Marcel, 2009) portrays despair as a significantly more cognitive emotion than fear, because fear does not need the judgment or deliberation of hope. In addition, the claim is made that hope is more central to the person's identity than is fear as despair might be associated with a disintegration of a person's identity whereas a person might not be so impacted by what they fear. For Marcel optimism is shallower than hope, as optimism does not require the kinds of judgments that hope does and is more a positive way of looking at the world based on a faith that things work out for the best. Optimism may be further contrasted with hope by considering the case of a patient with an incurable disease, where authors have claimed that we commonly think that while there may be, "little reason for optimism, don't lose hope"(Averill, Catlin, & Koo Chon, 1990, p. 96), suggesting that we can hope for things we are not optimistic will eventuate. However, despair extinguishes both optimism and hope as in despair the person is highly pessimistic about any reasons to have hope.

In despair, there is a feeling of being trapped and that one's existence in time has stopped. When despairing, one feels that nothing one does or thinks will change the situation as one's fate is inevitable or has been decided. Time is closed and there are no future possibilities. In such a state of despair, no further evidence is considered nor is further co-deliberation possible as everything seems futile. In despair one is closed to new ideas, dialogue or the comfort of others. In such a state, one is in abject solitude. Such feelings may be pre suicidal. "Hope, in contrast, maintains this

communal aspect to life" (Garrard 2009 p41).¹⁹⁹

To recapitulate, the awareness of what one may become, if one despairs, drives one to hope for a future, and assists us in our ongoing need to believe in something in order to feel a sense of control (Bering, 2012) and to avert falling to the despair that perhaps was Dante's conception of "Hell in the Inferno", where the inscription on the gates to Hell reads,

"Abandon Hope all who enter here" (Mittleman, 2009, p. 1). Averting despair has great importance in the spiritual and secular health domains. Though this is not the subject of this thesis, I will give an example from the religious sphere that I am not expert in. An interpretation of Christian teachings might be that to lose hope and turn to despair is to turn away from God and this is regarded as a great sin. In this interpretation of Christianity, despair implies loss of faith. In the secular health care realm that I have argued ought to be based on fallibilism and people's acknowledgement of uncertainty, despair is plausibly understood as including a rejection of the belief in the possibility of uncertainty as to what might transpire. A person in complete despair is certain that there is no future and that there is no point in trying to avert obstacles or prevail over challenges anymore.

Given the importance for health care of averting despair, it is prudent for patients and carers to give credence to beliefs that lead to more well-grounded hopes in health care, rather than to poorly founded grounds for hope. If one of the purposes of health care is to avert a patient's foreseeable path to despair, doctors ought to attempt to

¹⁹⁹ The solitude of despair can place a person in a state of mind that they accept no dialogue with those to whom respect is due as they see no point in attempting to find solutions as they see no way out. Despair undermines the important aspect of co-deliberation that is a keystone of ethical interaction between people as I discuss in chapter 2. To have a person removed from a society of co deliberators necessarily has great moral implications for the one who despairs.

warn a patient when patient's grounds for hope are considered ill-founded, where well-founded grounds for a health hope do occur. A patient ought not to believe that a health practitioner acts wrongly in attempting to dissuade them from what the carer considers to be ill-founded grounds for hope, as the patient ought to acknowledge that the carer is acting as a carer ought to act for the patient. The patient might disagree with the carer on what might be good or poor grounds, but the patient owes it to the practitioner to at least consider why the practitioner believes that the patient is on a path to despair through a misguided hope.

4.3 There are differing types of hope and hope in health care differs from hope in matters of spirituality.

I have already touched on this area by discussing “ultimate” and “fundamental” hopes. I now ask, “What is hope as it occurs in health care, and does it differ from other types of hope?” Importantly which type of hope ought a doctor and patient have dialogue over if one person feels that the others’ hopes are seen to disrespect or place undue burden on others? To return to questions raised at the beginning of this thesis: I claim that the objects of hope doctors and patients ought to discuss in health care rightfully are more secular than the objects of hope of religion. Health care has a much narrower focus than religion and involves assisting patients through changes in their life that often restrict their opportunities²⁰⁰. To gain well-grounded hope, patients need from their health practitioners data and advice that is as reliable and as salient to their health as is practically possible to reliably assess what to hope for in their health

²⁰⁰ See section 2.5.2

matters.

There is a kind of hope that is relevant to faith that is a “special type” of hope that belongs to hope of spirituality and religion but not hope of health care. Marcel writes of “hope against hope”²⁰¹ that may be a form of Godfrey’s “ultimate hope” whereby an agent may imagine that there is no chance of success for the object of hope, or might base hope on an imagination. Another kind of similar hope, is what Jonathan Lear calls “Radical hope” (Lear, 2008) where by in the face of cultural devastation the Native American Crow nation found a new sense of reality to hope for, through what their chief dreamed.

The Crow chief, Plenty Coups, recalled in 1928 to a trapper that; “when the buffalo went away the hearts of my people fell to the ground, and they could not lift them up again. After this nothing happened. There was little singing anywhere”(Lear, 2008, p. 2).

This expresses the cultural decimation that occurred when the tribes moved onto reservations and lost the previous means of defining purpose and honour in hunting buffalo and their warrior system was banned. The hopes that had been motivational became meaningless as there seemed to be nothing to strive for. Plenty Coups and his people followed his boyhood dream that led him to make peace with the Europeans and this dream became the basis for a new “ultimate hope” that the Crow nation would somehow flourish in the radically new world that Europeans inflicted on the first nations. This “ultimate hope” of the Crow for continued integrity had no basis in reality as Plenty Coups could originally have observed it but was based on faith in the power of dreams.

Radical hope and Marcel’s “hope against hope” accepts that the object of hope may

²⁰¹ However Marcel does not specifically use these three words.

be improbable but that some- how, by powers beyond that of the person who hopes, obstacles will be overcome and what is hoped for will prevail.²⁰² In religion a priest may claim that all followers need is the faith that the religion espouses, to hope for salvation. Radical hope may exist with (a currently perceived) high on zero chance of success in the object of hope²⁰³, but as argued below, such hope may render the agent highly vulnerable to despair, particularly in health matters in circumstances where viable more likely effective alternatives occur but are dismissed by the patient. Radical hope seems more common when there appear to be no other hopes possible. However ethical care encourages other objects of hope that may be more probable and tangible than always seeking cure when there is none foreseeable. The ethical use of hope in health care is best suited to a fallibilist model of the patient doctor relationship that has the ability to be responsive to each other's views and external evidence. As I will soon argue, the I.D.D.P.R. relationship is in part based on a premise that patients and doctors attempt to help a patient find new meaning with the change in their health (Carel, 2008)²⁰⁴, or *attempt* to understand (and if possible change) specific outcomes in the patients' health. Though indeed in health care causation might not be considered as currently assignable, by adopting a fallibilist attitude a person may acknowledge that they might in the future be able to assign a credible cause as new evidence transpires. Whereas if the object of hope is believed to be for ever beyond the comprehension of the one who hopes, that person might remain closed to even attempting to consider further evidence.

²⁰² Such hope rests on a person trusting that a mystical force will prevail to somehow achieve a state of affairs. Such trust might be construed as faith, discussed in chapter 5, where a person bypasses their usual more reasoned ways to find plausible objects of hope

²⁰³ Whereas false hope I have argued is a hope that is derived from sensory illusion or when a person at the same times hopes for something while they do not hope for it. Whereas "superman hope" is still genuine hope but is ill founded hope as it is impossible to achieve.

²⁰⁴ Discussed in section 4.6

A facet of a doctor's role can be compared to a caring teacher's role, in that the doctor assists their patient to find information to learn things about the patient's condition, and also assists them in considering what is more or less likely to occur in order to obtain a more informed idea of what to hope for. By contrast, the clergy may be believed to bestow upon their flock the word of a deity, and so guide parishioners to what the clergy take to be "the true and righteous path". Pastoral care has at its core a much broader focus than health care,²⁰⁵ and to confuse the role of health practitioner with that of priest is to lead to a crossover between the boundaries of the two domains and risks confusing patients and doctors alike. A priest may challenge my statement by saying that s/he involves her/his parishioners in the spiritual path to "show them the way", and the parishioners choose the path. However, "the way" is set by the religion that the clergy and parishioners subscribe to, and if either depart from that creed then it may be claimed by other followers of that religion that they are not "not true followers" of that "holy creed".²⁰⁶

Further if a person purports to be a health practitioner and is actually providing pastoral care, then they are deceiving the patient, and possibly themselves, as to their role. For example, consider a hypothetical example of a 1970s doctor, who was a member of the "right to life movement"²⁰⁷ who believed it was his duty to do all he could to dissuade women from having an abortion. This example might seem like a "straw man" (ie. a non-existent foil for my argument that never existed) however groups such as "Crisis pregnancy centres" are reputed to still use deceptive techniques to "make sure that women are fully informed"²⁰⁸.

²⁰⁵ By broad I mean large spectrum of hopes, beliefs and judgements that may provide reason for living in a way that thoughts about health do not give narratives to aspire to.

²⁰⁶ For more extensive discussion in this area see section 2.1a that discusses the nature of dogma.

²⁰⁷ While I will not provide a discussion of this movement, its members campaign against activities such as abortion, euthanasia, infanticide and certain other practices.

²⁰⁸ See; <https://www.newyorker.com/magazine/2019/11/18/the-new-front-line-of-the-anti-abortion-movement>

In a similar manner to his belief in evangelism, the 1970s doctor believed he ought to attempt to dissuade people from all abortions. The doctor would not declare his motives to patients as he believed that to do so might distract a patient from appreciating his important advice that other doctors do not provide. The doctor believed that this was not deceptive as he saw himself as telling women “the truth” about abortions that most of his medical colleagues concealed from patients. In another possible example, suppose an alternative medicine practitioner were also a member of the Church of Scientology, and – in keeping with my understanding of that group’s values– regarded psychiatric drugs as “evil” and believed that the alternative practitioner had a religious duty to steer all people away from these drugs. If consequently, the practitioner “nudged” a person who was previously in control of their schizophrenia away from their effective drugs by appealing to this patient’s biases, and by promulgating conspiracy theories, an empathetic rapport, attractive physical environment and claims that psychoactive drugs are “always bad as they are unnatural”, then, the practitioner was lying to the patient about their status and intent as a health practitioner. Indeed, they were acting in accordance with their Scientologist religious values rather than in their patient's health care interests – as viewed by the broader community they both lived in. I am not here claiming that the value of health care trumps the religious values, but that the above examples are of practitioners not representing the professional role of a doctor as is generally expected of them in the doctor-patient relationship. A patient may reasonably expect of a doctor that the doctor is seeing them to assist in their health care. Plausibly, it may be held by the patient that society dictates that doctors work within certain confines and doctors are not generally considered as qualified to give spiritual guidance. It may be thought unprofessional should doctors proselytise about any religion in the professional

setting, and covertly present their wider spiritual values as the basis of health care. Further support for this statement comes from Emanuel and Emanuel's argument for the I.D.D.P.R. whereby they claimed that,

The physician discusses only health-related values, that is, values that affect or are affected by the patient's disease and treatments; he or she recognizes that many elements of morality are unrelated to the patient's disease or treatment and beyond the scope of their professional relationship (Emanuel & Emanuel, 1992, p. 2221).

A doctor's remit in their professional role as doctor is health, not religion, as supported by Emanuel and Emanuel's deliberative model of health care, and medical degrees do not give doctors the training of a religious leader.

Both the above examples depict an immoral representation of health care if the motivations and intentions are not declared from the outset, as there is deception involved in engaging the patient in the first place. In these cases, loyalty to professional norms of behaviour and the duty to patient's health care are sacrificed by the practitioner acting with the intention of furthering a religious belief rather than act as we reasonably expect a health professional ought to act. The practitioner owed it to the patient to be honest in explaining that the object of hope the practitioner offered, to be well off all psychiatric drugs, was premised on a belief system that rejects mainstream psychiatric medicine due to a religious belief. The patient gaining informed hope was disadvantaged as the patient did not have access to alternative well-grounded beliefs in the setting of an ideal deliberative doctor-patient relationship where many beliefs may be openly appraised.

4.4 Health practitioners ought to be careful in how they attend to the emotional aspects of the consultation in order to support a patient's informed hope and not "destroy" a patient's grounds for hope.

There is a critique of using the process of E.B.M, arguing that the process is overly rational and does not facilitate practitioners in their offering care, as the process often enables in people little or no grounds for hope (Ernst & Hung, 2011) (Sencer & Kelly, 2007) (Adams & Jewell, 2007). (Daneault et al., 2006) For example, a well-known T.V program called "House M.D." characterised this notion whereby the doctor is overly rational and is portrayed as only interested in "the facts" and not the "human" side of care and hope. A second critique of utilizing E.B.M. processes that I will discuss in more detail in this section argues that doctors "destroy hope" by giving overly pessimistic estimations of prognosis. Against these critiques I will argue that while exceptions may occur, generally E.B.M. processes neither ignore the importance of the ethical use of hope nor destroy grounds for hope when cure is uncertain or unavailable. On the contrary, E.B.M. processes are capable of providing doctors with a basis for promulgating well-founded grounds for informed hope, and for the formation of new hopes.²⁰⁹

Great harm may be brought upon a patient who is offered misguided grounds for hope²¹⁰ where there are more plausible and more probable health possibilities to hope for, in cases where the patient is diverted from effective care. What follows are examples of such. These cases illustrate two differing ways in how people who represented themselves as health carers failed in how they ought to have promoted

²⁰⁹ For example, by assisting a patient to develop well-grounded hope for a dignified time of dying, or that the medical team will be there for the patient in their time of need and will always respect the patient.

²¹⁰ By "misguided grounds" I mean foreseeably believed to be misguided by the overwhelming evidence and conventional interpretations of such evidence and norms of reason by the community, practitioner and patient.

well founded grounds for hope to patients. One practitioner attended to the emotional grounds for hope but provided ill-founded objects of hope. The other practitioner was not able to provide what would have been well-founded grounds for hope. This is because he failed to attend to the emotional component of the patient's hope as he ought to have by not attempting to engage in care based on the schema of the three constructs that acknowledges the importance patient's perspective and feelings.

Ralph (a fictive composite example from many patients or cases that I have read about) was a 38-year-old man who had seen a G.P. (General medical practitioner) for ten years to help him with: marijuana abuse, the pain of an abusive childhood, and difficulties in trusting people and forming relationships. In the past, Ralph had a skin condition that he found improved after consulting a naturopath, after various steroid creams had given only short-term benefit. A G.P. locum referred Ralph to a competent urologist after tests revealed that he had testicular cancer. The urologist offered mainstream options that involved a multidisciplinary team of nurses, surgeons, oncologists and radiotherapists.

The urologist was an hour behind schedule when he saw Ralph and appeared irritated that Ralph had no private health insurance cover. The urologist advised Ralph of a management plan for treating the cancer that was handed to Ralph without much discussion, and Ralph found the diagnosis, the consultation setting, and the long wait, stressful and uncaring. After the appointment, Ralph did not take up the usual therapy that a process of E.B.M. might have guided him to, partly because he thought that the urologist treated him "as a number" and did not seem to care about him. Instead, Ralph attended "Professor Norm", an alternative medicine proponent, who was confident that he could cure Ralph. Ralph was also advised to

take special supplements that the professor imported from America, that were purported to have "scientific studies behind them" proving their efficacy.

Ralph was given contentious "grounds for hope" of cure by Professor Norm. The professor "informed" Ralph that the success of what Norm advocated "had been suppressed by conventional medicine". Ralph had always felt on the edges of society and identified with being part of a group which rejected establishment conspiracies. As Ralph trusted Professor Norm as a "likeable bloke" and as Professor Norm seemed sure that he could cure Ralph without gross surgery and chemical and X-ray bombardment, Ralph was satisfied with alternative treatment, especially because the naturopath's ideas of natural alternatives were in line with his own beliefs.

Ralph found that Professor Norm seemed to "give him hope". Norm said to Ralph he was sure that he could cure Ralph, and he seemed committed to Ralph and made Ralph feel heavily involved in the treatment. Ralph had to pay large sums of money for the Vega machine hire²¹¹ as recommended by Professor Norm, consultations, and to obtain the special supplements. Ralph was busy three times a day²¹² with using the Vega machine, had to meditate in a special way as Professor Norm prescribed with

²¹¹ A Vega machine is a device that is alleged to measure the body's electrical signals and is believed by some people to be a means to assess aspects of allergies or health. It was invented by Mr Voll in the 1950s and has been repeatedly disproven to have the functions claimed of it, by processes of E.B.M. The Australian Register of Therapeutic Goods with draw its listing as a product that could be sold for health care in Australia in 2010, though the author continues to have heard anecdotes that it is still used. Though Ralph's monitoring seemed to be careful in the sense that a lot was going on, I debate that such monitoring was caring, if we believe care involves helping a patient overcome obstacles to their health.

²¹² Frenetic activity billed as therapy can lead to disappointment. Having a patient take a host of supplements, follow an onerous diet, read prescribed texts, undergo certain meditation techniques, is more honestly "activity planning" as part of Cognitive Behavioural Therapy, a common counselling technique, in an attempt to maintain positive mood or hope that such activity will achieve a health outcome. Frenetic activity could be used and be anything that patient feels helps them, even if it does not in itself make any difference to the disease directly. Such activity should be declared as activity planning and not "sold" as being more than that, as to do so would be deceptive. The naturopath reviewing "natural treatments" with live blood analysis, iridology and Vega machine testing is getting the patient back to multiple consultations but is not caring for the patient's well-grounded health hopes. By this poorly grounded model of health care, where it does not matter whether the treatments are viable or not or the tests are valid; it seems that the volume of activity purports to be proof of ongoing care. However, the volume of activity does not necessarily equate with care, let alone effective care. Keeping a patient busy is not necessarily sound health care, as though the patient may feel empowered being involved in their care, such care is in fact uncaring if it is promulgating grounds for false/misguided hope, while the practitioner profits

patented mantras that Ralph followed and had a low sugar diet to “starve the cancer”. Ralph also read many so-called research papers that appeared to him to be “scientific” that supported the use of the supplements which claimed that this treatment was being suppressed by the process of E.B.M. All of these factors seemed to Ralph to make Norm an authoritative figure who was trustworthy, who was “on Ralph’s side”. The urologist was however to Ralph on the “other side” i.e. an “E.B.M.” doctor.

Norm’s emotion of hope felt “emotionally contagious” to Ralph, as Norm seemed to have such strong hope that he could cure Ralph. Norm was such an authoritative figure to Ralph, and Ralph felt that Norm was one of a group of “outsiders” like he was. An “emotional contagion” has been defined as, “a process in which a person or group influences the emotions or behaviour of another person or group through the conscious or unconscious induction of emotion states and behavioural attitudes” (Schoenewolf, 1990, p. 50). Furthermore, it is claimed that if a patient is subject to an emotional contagion effect, a patient might adopt less than their usual process of deliberative appraisal of all the relevant evidence. “Emotional contagion is relatively automatic un intentional and uncontrollable and largely unconscious” (Hatfield, Cacioppo, & L. Rapson, 1992, p. 153).

Patients may deny salient evidence due to many cognitions, such as having certain biases, perceiving certain authority figures as a member of their “outer group” and so as more trustworthy sources of evidence (Gorman & Gorman, 2016) than evidence present from other sources. However, patients owe it to themselves to be mindful of bias and emotional contagion effects that might influence them to make imprudent choices about the grounds they choose to be the basis of what they hope for in their health. Furthermore, doctors and patients ought to be mindful of emotional effects that

might impair their usual deliberative processes particularly where those they respect around them seek to challenge a belief that either person claims is derived from a process that is less well deliberated upon than what the patient or doctor would normally expect of themselves.

While I have argued that it is not conceptually possible to give another person hope, it seems plausible to hold that some emotions of other people may nonetheless be attractive, easy to adopt or suiting to an agent's situation. It seems possible that if emotions such as anger or joy might be infectious, then so too might hope be infectious. Anger may be more or less infective in differing circumstances, and anger may be real but unjustified. The emotion of hope is more complex than anger in that hope is forward looking and involves more complex judgements in the case of hopes in health care than are required in coming to the emotion of anger. The conception of hope that I have argued health practitioners and patients ought to work with, is the type of hope that allows for deliberation and some diligence (by doctors and patients) in encouraging that the hope is well informed and well-grounded while also being attentive to the emotional aspects of hope.

While a person may be infected by the anger or love of another person in personal relations, it seems uncontentious to claim that it is unprofessional and unethical for a doctor to offer treatment based solely on the strength of the doctor's emotional feeling of hope. We reasonably expect modern doctors who operate in a model such as that of the schema of the three constructs, ought to treat patients while respecting principles such as informed consent, based on what is important for the patient, not the doctor. The strength of a doctor's passionate hope for a cure ought not to be the main basis for a patient choosing what they ought to hope for in the health, as such a choice is doctor-centred rather than patient centred.

In patient centred shared health care decision making such as occurs in the model that I have argued for, while the patients' interests are rightfully the basis of the relationship, the strength of emotional feeling that a patient attaches to an object of hope, ought not always determine what doctor and patient ought to hope for, or how they ought to make decisions that increase their chances of attaining what is hoped for. A strong emotional attachment to a belief, might distract a patient from seeing what is prudentially in their interests²¹³. A patient's strong emotional attachment to a belief, that leads to an "ultimate hope the patient is committed to", might also have a contagion effect into their usual deliberative processes thereby leading them to refuse to consider the beliefs of health practitioners to whom they owe attention or how what they hope affects others.

In the above, example, the ethics and behaviour of both the practitioners, Professor Norm and the urologist, comes into question. The urologist offered well-founded grounds for hope and offered reasonable grounds for being considered trustworthy, but the urologist's poor attempts at rapport negated the clinician's understanding of Ralph's abusive past, and of his particular circumstances. While the urologist offered a solution for changing Ralph's health situation that was "rational" in representing the middle ground curative options derived from the process of in E.B.M., s/he nonetheless ignored the importance of emotions and feelings in individuals determining what health care choices they might possibly hope for. The urologist provided well-founded grounds for hope, by giving accurate data, but did not frame the information in a way that Ralph was willing to accept as grounds for hope.²¹⁴ The urologist failed to utilize the holistic E.B.M. process that is based on the patient, their

²¹³ "Their interests", being what they usually have believed to be healthy for them.

²¹⁴ The urologist seemed sterile and quite "uninfectious" in his emotions.

beliefs and situation, not only clinical acumen and trial data.²¹⁵

In contrast, Norm seemed to Ralph to offer hope, when hope was not Norm's to give,²¹⁶ and when the grounds for such hope was fantasy. Furthermore, Norm was plainly untrustworthy and was deceptive in purporting to be a health authority when he was in fact barred from practice by the medical registration board.

The circumstances of the consultation, with lengthy waiting time, Ralph's perception of the urologist's disapproval of him as he had no health insurance, the urologist's use of technical and medical terminology, and what Ralph perceived to be an involved and painful treatment created, for Ralph, an unpleasant experience. The urologist did not assist Ralph in gaining an understanding of his options, but rather simply presented facts without attempting to help Ralph comprehend them. While the urologist breached a duty of care in not providing a setting conducive to informed consent, s/he also failed in his/her duty as a doctor to give Ralph information that he needed in a comprehensible way so that he could best understand what he could hope for.

The urologist's seemingly emotionally cold way of dealing with Ralph, seems to point to a weakness in the way E.B.M. process is sometimes practiced, in that the calculated weighing of the best available evidence is construed as ignoring "giving hope" (though not literally) as not demonstrating care. The fallibilist form of scepticism that is integral to the E.B.M. process is seen by some patients, who feel disenfranchised by it, as an indifferent to them, and as non-supportive of them (Adams & Jewell, 2007; Vincent & Furnham, 1996). Given that there are many conditions in medicine where there is, at

²¹⁵ The accounts of the process of E.B.M. I have discussed, guide doctors, where possible, to involve the patient in dialogue into their care. So to Emanuel and Emanuel's ideal doctor patient relationship and Scanlon's account that rely upon co-deliberation between two people can be linked to the ideal process of E.B.M. in the manner that two people ought to attend to the other person and deliberate together upon a decision that impact both parties .

²¹⁶ Ralphs hopes did not belong to Norm, and therefore conceptually it was impossible for Norm to give Ralph hope. In the account of hope I referred to "Hope is an emotion of an agent..."; hope belongs to that agent. Indeed agents may hope for the same things, or share grounds for hope or be inspired by others to imagine other grounds for hope, but hope resides in that agent.

this time, no direct clinical path in the process of E.B.M from ailments to treatments, it is little wonder that patients seek other modalities in which a pathway appears to be clear, and in common expression, “hope is given”. However, often this is misguided hope and is not a basis for ethical health care, as there is both a misunderstanding of the nature of hope (since hope is not the carer’s to give) and of its ethical use in health care, in that effective health care requires well-founded grounds for hope with at least some reasonably foreseeable chance of attainment.²¹⁷

The fallibilist attitude of those who refer to the process of E.B.M. is not demonstrative of a lack of care, but is an honest and useful part of determining what best available treatments are available to co-deliberate upon.²¹⁸ The urologist failed in his duty of care to appreciate Ralph in his individual context and due to time pressure, financial considerations, or indeed prejudice about what he perceived of Ralph, did not present the “facts” (as the urologist saw them) to Ralph in a way that Ralph could absorb them. Merely presenting “the facts” is not fitting for the I.D.D.P.R. or how the process E.B.M ought to be practiced and fails to assist patients to learn what they might possibly hope for.

It may be suggested that the urologist not only did not frame information in a way that could assist Ralph to gain “informed hope” but that the urologist destroyed grounds of hope for Ralph, who then had to seek hope from a source other than doctors. By offering modalities that seemed alien to Ralph (due to the manner in which they were presented), the urologist offered no grounds for hope that Ralph could assimilate into his world view. The urologist’s poor communication was hardly befitting

²¹⁷ Even if a patient is unconscious then that the person, before they were so vulnerable, would hope that carers would look after them when so vulnerable. A neonate may not have hopes at that stage but the future person the neonate may become, would hope that they were cared for as a baby, or the family of neonate may have hopes for their non-sentient, non-hoping baby.

²¹⁸ As I argued the first two chapters.

of the schema of three constructs that the urologist ought to have fostered. To quote another author who writes on the issue of surgeons not attending to the mutually respectful relationship patient doctor relationship as they ought to in the context of hope,

“Poor communication, pessimism, and an impersonal context for disclosure diminishes hope”(Suri, McKneally, & Devon, 2014, p. 1629). To illustrate the suggestion that a doctor can promulgate destroying grounds for hope where well-founded grounds for hope exist, consider a fictitious case of a neurosurgeon who advises a family that their child’s chances of emerging from surgery without major handicap are very low, or that survival is less likely than plausibly is the case. The surgeon may be motivated by several factors. She may “not want to get the family’s hopes up” and then have the family disappointed and angry with the surgeon. Or the surgeon may hold a view that it is more caring to “assist” patients and families to “prepare for the worst” so that should death occur they are more prepared. On the one hand advising patients to “not get one’s hopes up” could seem to be compassionate care as this may facilitate a patient in evolving new hopes other than cure. On the other hand, such a strategy may “backfire” and lead a patients/families to unnecessarily despair if they can see no hope but only see that death is at hand.

A solution to this problem is to argue that a health practitioner has a moral duty to represent to the patient (in a sensitive way that the patient can comprehend) the level of uncertainty²¹⁹ that lead the health practitioner to hold various opinions on the matter at hand. Plausibly there is uncertainty as to what might eventuate in a clinical setting and by adopting a fallibilist attitude the practitioner approaches clinical decisions with a degree, even if minimal, of uncertainty. By acknowledging their degrees of

²¹⁹ And in addition, biases that held by the carer is aware of.

uncertainty (to themselves and the patient) the practitioner's opinions and how they arrived at them may be open to discussion with the patient and family.

The practitioner might judge that if they were in the patient's position with, e.g. with a 2 % chance of survival, that this would lead the practitioner, while not rejecting outright the strong hope to survive, to look to develop hopes other than just to survive. While holding that strong survival hope based on 2 %, the practitioner would likely imagine other hopes and pathways to maintain meaning, should death seem more inevitable.²²⁰ The respectful practitioner recognizes that people can appreciate risk in a different way to them and the practitioner might show respect to the patient by offering to have dialogue about why the practitioner and give credence to the same risk if differing ways.

Just as it may be harmful to encourage misguided hope, it may be egregious to deliberately act to destroy or degrade a patient's grounds for hope when there are grounds for hope that are well-grounded, possible or probable. Practitioners may have different motivations to sabotage a patient's chances for hope. A surgeon may be overly worried about protecting their assets and not being sued in case surgery goes wrong. Or the surgeon may want to be seen as a heroine who saves "hopeless" cases. Or perhaps the surgeon seeks to command a higher fee as the surgeon "is the patient's only hope". In these three latter examples the doctor's wrong of putting self-interest ahead of patients' interests is a betrayal of trust (chapter 4) and fails to support a patient's need to form well-grounded hopes. While hope for survival or cure may not be given in every clinical encounter, it seems the antithesis of empathy and

²²⁰ While I am not claiming that a carer must always "put themselves in the patients' shoes" and attempt to feel as the patient does, I suggest that the carer may discuss with the patient how the carer comes to attribute value to levels of risk, given the carers understanding of the patient situation. With such dialogue the patient may correct the carer of mis-grounded understandings of the patients' situation and the carer may better understand what a patient may or may not comprehend in realising what it is possible to hope for.

compassionate care to let patient despair when real hope is available.

Some practitioners may attend more to emotions and feelings in comparison to some (other) practitioners, but while rapport and empathy are important to the carer/patient relationship, such components of care though often necessary, are not sufficient for effective ethical health care. In using the ideal process of E.B.M. a practitioner who is really, “merging clinical acumen with best available evidence and patient values” and the patient’s situation (David L. Sackett, 2000, p. 1) is able to offer effective care if they are able to address the domain of the patient’s feelings as many practitioners do, with the added power of best evidence for care measures. It is a “straw man argument” to suggest that the role of a doctor who uses E.B.M. processes is purely to give data or to represent to a patient what the guidelines dictate, as guidelines do not “tell” a doctor or patient what to do in their unique situation but are a reference for dialogue.²²¹

The urologist’s failure to be compassionate and failure to offer the patient an opportunity for an adequate dialogue, amounted to a breach of duty of care and violated reasonably expected standards of informed consent. However, this was due to ineptitude, or to personal, or systemic pressures and was the urologist failing. Such failings are less morally wrong than those where a practitioner deliberately offers false grounds for hope. The former errors are also less morally reprehensible than are deliberate betrayals of hope and trust. We ought to accept that errors may occur and we should excuse mistakes more so than we would deliberate deception, partly as in the schema of the three constructs that I claim ethical health care may be based upon, we may accept that we are all fallible and may make mistakes; after all even a virtuous person might make a mistake.

²²¹ See chapter one.

Deliberately facilitating grounds for misguided hope can undermine a key element of what makes a person a unique individual, and thus violate that person's autonomy. To maliciously undermine a person's grounds for hopes when they have trusted a doctor²²² to assist them with their hope object of hope, and to consequently allow a person slip into a state of despair, because the doctor's actions facilitate their particular dread, is especially wrong. Professional ineptitude is a failing of character and of virtue that should not be condoned, but deliberate deception undermines the trust that is owed to each other in the ideal of the schema of that links the three constructs. In the next part of the discussion, I examine how Professor Norm behaved unethically, not only by standard bioethical measures such as deferring effective care, betraying trust, and practicing outside his "professional" competence, but also in setting up and stoking a fire of misguided hope.

4.5 The consequences of supporting foreseeably misguided or false hope in health care.

In this section I will argue that giving grounds for foreseeably misguided hope is especially egregious as it:

- A. Might undermine a person's autonomy and lead them to despair
- B. Involves the carer taking on too much responsibility for the patient
- C. Dispenses with a realistic appraisal of the patient's health situation and may misrepresent hope as an end in itself which it ought not to be in health care.
- D. Ultimately demonstrates a lack of care

²²² In addition, this holds for any person who represents themselves to be a caring health practitioner.

To elaborate:

- A. Might undermine a person's autonomy and lead them to despair

To culpably give grounds for misguided/ill-founded hope might undermine the recipient's core life plans and might be a more significant wrong than, for example, acting beyond one's professional boundaries, or ignoring informed consent. In support of my claim that hope is associated with life plans I quote from Barilan who wrote that, "Hope is the embrace of promotion- focus goals as important elements in a life-plan" [where] "Promotion focus is a mode of action that is directed at future goods" (Barilan, p. 169).

For a doctor to knowingly provide grounds for misguided hope not only violates trust (as a doctor ought be trusted to assist a patient in well-founded hope) but can culpably allow a patient to slip onto a path towards despair.

To have a person linger in a state of depression after a severe irreversible stroke unable to speak, or move, might lead to a protracted existence in a despair which might plausibly be regarded as worse, for that patient, than death (and indeed some might not even regard death as "a bad thing" for that patient). The patient may consider such life to be a "living death". The actualized anguish, that the patient hoped to avert, might constitute a significant harm caused by an unethical carer, worse than death, physical hurt, or the act of being deceived itself. To undermine a person's hopes, or to push them, towards hopelessness is particularly injurious as the unethical practitioner is going against a patient's interests, in not aiding the patient avert that which will cause them to despair. In sharing with a practitioner what a patient hopes for, the patient confides in the practitioner the path to despair that the patient seeks to avert and might uniquely expose their vulnerability to the practitioner. Such a clinical circumstance

serves to highlight the relational aspect of hope in health care and that practitioners owe it to their patients to be particularly attentive to a patient's hopes. Christy Simpson writes on the relational aspect of hope that I use to illuminate the factor of hope in the doctor-patient relationship.

There is a sense in which sharing one's hopes with these 'chosen' others can help to create intimacy (for an individual will often not share her hopes with everyone), but the price of this intimacy is being 'exposed', and hence vulnerable, to the reactions of these others (C. Simpson, 2004, p. 444).

In the schema of the three constructs that I draw upon, the health practitioner owes it to the patient to place a high value on being trusted with such profound information about another person and (out of respect for the patient and their role as a doctor) owes it to the patient to do with such personal information what the patient expects of the practitioner.

The health practitioner who knowingly gives grounds for misguided hope²²³ while claiming the opposite, acts particularly wrongly as they are lying about something that is of value to a patient and has inappropriately used a patient's vulnerability that the practitioner was entrusted with. In these circumstances a health practitioner acts unethically when they advertise their service as caring, or as being able to aid a patient achieve health goals, when the unethical practitioner is doing no such thing.

If the health practitioner is merely using a patient as a mere means to an end, be it financial, or to confirm the practitioner's world-view (or even their own hopes), then they are also being disrespectful to the patient, and their practice is not only manipulative but deceptive. In summary, there are two ways of analysing the wrong of doctors giving grounds for misguided hope, firstly, as deceptive in violation of both

²²³ That are the types of grounds for hope as relevant to the hope of health care that I have argued for.

patient autonomy and some normative codes of conduct, and secondly, as it may severely harm a patient to promulgate grounds for misguided hope that the patient follows or finds hard to resist.

Health practitioners ought to honour what the patient has come to have as an object of hope with the special co-deliberative relationship where both have agreed upon what they owe each other. Practitioners owe it to their patients to hold patients' objects of hope in the highest regard and to realize how egregious it is to disregard the importance of their role and break what they have promised to do. In turn a patient ought to recognize and acknowledge the degree of commitment that they place on a practitioner by trusting the practitioner, precisely to care for them through what they hope for.

B Giving grounds for foreseeably misguided hope is especially egregious as it involves the carer taking on too much moral responsibility for the patient.

A practitioner might give a patient grounds for misguided hope for a cure, in circumstances where there is widespread belief by those who have appraised the practitioner's "cure" with E.B.M. processes and have found that the grounds to give credence for the practitioner's "cure" are ill-founded. Such a practitioner might believe that their "therapy" offers objects of hope that fit Aquinas's criteria as the objects are "agreeable, arduous, attainable and future" and the carer has no intention to deceive. However, such a health practitioner takes on a major responsibility in a way that may place the patient in harm's way.

However if on the other hand, a practitioner uses processes of E.B.M. to guide their dialogue with a patient and the health outcome hoped for fails to eventuate, the

practitioner has at least acted as many other medical practitioners would have acted who do their best to offer advice guided by process of E.B.M. The responsibility for error and success in such a case is in a sense a team effort with the input of many practitioners and researchers on a world-wide scale, now and in the past, forming E.B.M. based therapeutic views that guide patient care. Grounds for misguided hope given *in error* by a fallible health practitioner practising within processes of E.B.M. may be done with the best intentions, and in conjunction with many people, thereby reducing the scope for self-interest, or for motives other than patient care.

To act ethically, practitioners who operate without being guided by the appraisal processes of E.B.M, owe it to the patient to inform the patient that the object of hope that they offer is possibly not widely accepted as having a large, or robust, evidence base. The possible grounds for hope that such a therapy offers, might lead to less well-grounded hope, than may the objects of hope offered by a therapy that has or is being appraised by E.B.M. processes. For example, if I as general medical practitioner prescribe a medication that has not been appraised by E.B.M processes²²⁴, I ought to inform the patient that such a medication might not have a well-grounded basis for their object of hope, possibly other than the basis of my clinical acumen, or what is commonly prescribed by doctors.

I examine examples of practitioners taking on too much responsibility such as Norm's treatment of Ralph in the above fictive composite example, and in the notorious real case of New Zealand's Associate Professor Green (Sandra Coney & Women's Health Action., 1993) taking on excessive responsibility for women's health hope objects, as he did not advise them either of their condition or of their options. Herbert

²²⁴ For example, by "off label prescribing", see <https://www.nps.org.au/australian-prescriber/articles/off-label-prescribing>.

Green was a prominent gynaecologist and head of department at Auckland's National Women's Hospital who conducted a longitudinal observation study into how cervical cancer evolves from "Pap. smear" anomalies. Green ignored mounting scientific data against his postulation that cervical carcinoma in situ did not progress to invasive cervical cancer. As his own data evolved, showing that his theory critically impaired his patient's lives, he rationalised against this data, and similarly discounted the evolving worldview that he opposed. Associate Professor Green acted as an isolated health carer and chose to not follow usual standards of informed consent and the consensus of the world view that prevailed at that time about how cervical cancer developed from initially minor "Pap. Smear" changes.²²⁵ Professor Norm, too, acted on his own. Both men bore great responsibility for their patients' harms and deaths that may have been averted if the patients had had a chance to be more informed in their health care. By withholding the abnormal pap smear results from women, Green took on too great a responsibility for making choices about those women's health. Whereas in a model of health care supported by the schema which linking the three constructs, the doctor owes it to the patient to share such results so that a patient might prepare for, and seek solutions to, obstacles in what they hope for in their health. Green owed it to the women to release to them their Pap smear results and by withholding from these women their results he betrayed the women in his duty to assist them to be informed in what they could hope for.

²²⁵ Green's Unfortunate experiment occurred in the 1960s to 1980s, so it might be claimed Green's research methods were standard before the time the process of E.B.M. was being developed. The E.B.M. system first became widespread in the early 1980s with work of David Sackett and then Gordon Guyatt. However, the very notion of "informed consent" that Green's methods violated had been broadly discussed from the 1950s and were even more widely discussed in the early 1970s (Beauchamp, 2011) while Green's experiment continued until 1987. Even before the process of "E.B.M" was being discussed, Green was conducting harmful research by the standards of his time and the world wide view was not in accord with Green's view.

C. Dispenses with a realistic appraisal of the patient's health situation and may misrepresent hope as an end in itself which it ought not to be in health care.

To return to the third point of the discussion, culpably giving grounds for misguided hope is especially grievous, as it might deprive a patient of an adequate appraisal of the patient's health situation. Rapport and care are key aspects of being a health carer but ultimately health care requires results so that patients may have "informed hope" and can choose as well as possible what they might hope for. Showing care and compassion may occur in other fields such as pastoral care, but uniquely health care also needs to aid patients to properly appraise their health situation and to make adjustments accordingly. In this way the process of health care that refers to processes of E.B.M. and promulgates aspects of the I.D.D.P.R. as supported by doctor and patients determining what they owe to each other is more compassionate than seemingly empathetic futile care because it helps a patient achieve what they hope for.

A clinician might make the claim that a dying person should be "offered" misguided or even deceptive hope as the hope itself could have some therapeutic effect when there is "nothing else". The clinician might hold that without offering some grounds – even if poorly founded grounds – for hope that they are abrogating care for the patient. I contest this claim. Insisting on an option that is allegedly therapeutic does not necessarily make it the most ethical care. Such thinking borrows from the notion that "We can't just stand there and do nothing. Do something, anything!!" (This is not a quote but represents an idea from David Sackett writing of his recollections of futile heroic treatments at a time of a Polio epidemic) (Silverman, 1998). Not only may one question the role of placebos and deception in "giving hope" that might or might not

have therapeutic effect, but importantly such deception might rob a person of the opportunity of hoping for other things that are of great value for them before they die. In refraining from acting in ways which some might construe as “giving hope” (that I argued is conceptually impossible) a clinician is not abrogating care but is showing greater care by showing respect for the patient and enabling a new, perhaps terminal, phase of care to develop. New, ultimate hopes have a substrate to arise from, when a patient appreciates that they are closer to the finitude of their life journey.²²⁶ If the clinician gives a patient ill-founded grounds for hope because the clinician believes that hope is an end in itself and has a therapeutic role where there are no other therapies left, then any deception here is done to a vulnerable dying person who has trusted that carer. By not aiding the patient to develop informed hope the carer is robbing a vulnerable person of power to make their final choices as they die, and this is deceptive and an abrogation of what a carer owes to the patient.

D The consequences of supporting foreseeably misguided hope in health care ultimately demonstrates a lack of care.

Part of a carer's purpose is aiding people in being realistic in what they can possibly hope for, recalling that hope in health care ought to be foreseen as attainable by the patient. A caring nurse or doctor gives a patient the impression that s/he is acting in the patient's interests and shows empathy for the patient, by aiding the patient in what they hope for, be that recovery, comfort or illness prevention. These hopes are the patient's hopes and I have said that a role of health care is to assist a patient in understanding what they can plausibly hope for. To deliberately betray a patient's hope or offer false grounds for hope represents an abrogation of care.

²²⁶ By honestly fostering environments for informed, well-founded grounds for hope in health care, the clinician enables the patient to have increased potential to re-appraise their hopes in light of new ideas.

A practitioner owes it to the patient, society and themselves to have certain professional values such as a high degree of integrity and honesty. Care can continue even if the carer cannot give “good news”, if the carer communicates in a sensitive way. In giving “bad news” there are considerate ways to tell a patient that they are, for example, going to die soon, versus purely going through with a patient the options as are known for the average person at what we think their stage of disease is. To quote Suri in the context of the delicate discussion of truth in end of life care, in the context of a carer attending to a patient’s emotions and what they hope for,

“Truth telling should be regarded as a process through which the truth is developed and revealed progressively, sensitively, and skilfully to help patients understand and live with their illness, while maintaining a strong sense of hope”(Suri et al., 2014, p. 1630).

Suri’s claim supports that in the clinical setting honesty should not be brutal but may be caring and is more caring as it reinforces to the patient that one is acting with their interest at heart and will not deceive them. It is not contentious to claim that in all but exceptional circumstances, doctors ought to be honest with their patients. A patient ought to be mindful that the carer is committed to be honest with them and that a carer ought to give the patient the chance to be aware of beliefs (and the basis for such beliefs) that do not support what a patient hopes for. Suri also points to a commonly held belief about the importance of maintaining hope in health care that I discuss in five pages. While hope can be strongly held as feeling it also may be strongly grounded, not only epistemically but in the basis of how a person has considered how their “strong sense of hope” affect others. Part of any account of care in the context of the schema of the three constructs that I link through this thesis is that to care for a patient includes caring about a patient’s hopes.

4.6 Ethical health care in relation to well-founded and informed hope or ill-founded misguided hope.

Drawing on the work of Havi Carel (Carel, 2008) and Gabriel Marcel (Marcel, 1951a), an important part of the "compassionate care" of health care is to assist patients to avert despair where well-grounded objects hope are considered to be possible. Compassionate care may aid patients to imagine new possible hopes when options are foreseeably receding and so carers may aid a patient to avert the isolation and self-implosion of total despair. A part of Carel's claim in developing an account of "health care" is that health care is directed at aiding people to accept and find new meaning with their changing life circumstances and options as they progress from birth to death. Health care is directed at assisting patients to adapt their autonomous position to their inevitable growth change and decline. Health care can aid patients to reach the health goals they want or adapt to changes in health and do the best with what they have. This form of care is acting with the patients' interests as the goal. It involves a connectedness, and a supportiveness, so that the patient is not alone but has a guide or adviser for facets of their autonomy.

Narrower conceptions of health place a carer's role as assisting a patient to regain health; be that correcting pathology (Daniels, 1985) or a broader biopsychosocial account of health (Misselbrook, 2014). However, from my representation of Carel's work it seems plausible to hold that the health carer's professional relationship with the patient has an important relational aspect. I am not here arguing that ethical health care requires that carers give patients grounds to believe that a doctor-patient relationship is some sort of friendship, nor is that akin to the relationship of priest to parishioner. However, as I now argue that compassionate ethical health care requires a unique relationship as such may occur when a doctor and patient agree to a

relationship in the schema that links the three constructs discussed in my first two chapters.

One account of compassion places compassion as, “a virtuous response that seeks to address the suffering and needs of a person through relational understanding and action” (Sinclair et al., 2016, p. 195). Compassion needs to be contrasted with empathy in the doctor-patient relationship. Empathy has been construed as, “the capacity to share the feelings of others whereas compassion is feeling for and not feeling with the other” (T. Singer & Klimecki, 2014, p. 875).²²⁷ Importantly, care that involves compassion can be construed as more than bearing witness to or feeling another’s suffering, but importantly involves *effective* care to assist the one who suffers. For that reason, supporting ill-founded or misguided hopes fails in the compassionate part of caring, if there are well- founded grounds for hope that are effective in assisting the one who suffers.

Supporting grounds for misguided hope might seem empathetic but it is not compassionate, as although being complicit with a patient’s misguided beliefs might seem empathetic and initially seeming friendly, it might not be effective in assisting the patient avert what might hasten their path to despair. I do not claim that friends are always necessarily empathetic but not compassionate, nor that health carers ought not to show a patient empathy. However, while a carer who “goes along with” or offers a foreseeably futile treatment path, may intuitively seem a more caring, friendly or empathetic person to the patient, such care might actually be less compassionate than sensitive communication in the schema of the co-deliberative process that links the I.D.D.P.R., the process of E.B.M. and a patient and doctor determining what they owe

²²⁷ One author suggests that there are at least four kinds of affect that are all called empathy: affective empathy (proper), emotional contagion, personal distress, and sympathy/ empathic concern (Maibom, 2017).

to each other. Facilitating foreseeably misguided grounds for hope while the doctor is acting in some sense as a friend, might help a patient to achieve immediate gains in some of what the patient hopes for (for example feeling supported by their carer), however, such a course might foreseeably lead a patient to despair when more well-founded grounds for hopes were subsequently understood by the patient to have been possible.

Being friendly to someone is not necessarily caring for them in the way a nurse or doctor cares for a patient. There are risks to patient care if doctors befriend patients, so too patients ought not to choose a health practitioner as they would a friend, nor should they confuse professional care with friendship. We may borrow here from the work of Charles Fried who contrasts professional relations with friendships. Health practitioners are not friends as there is not necessarily the longevity of friendship nor the sense of mutual commitment between a health carer and a patient. In short, there is a power imbalance, the carer's motives are in part financial, and doctors must often care for people that they do not like. Though Fried discussed relationships between clients and a legal professional (Fried, 1976), I draw the previous claims from Fried's work. We see patients trust and receive effective care from medical practitioners that they do not like (for example, an aggressive surgeon who we admire for her/ his technical ability, not for their bedside manner). On the other hand, though a patient might experience what they regard as a friendly feeling towards a practitioner, such a feeling is not a necessary nor a sufficient condition for the kind of compassionate care that fosters genuine, informed hope.

Just as ethical doctors ought not to offer grounds for hope of being a patient's friend, nor ought doctors while acting as a health professional offer patients the doctor's own religious belief as grounds for the patient's spiritual hope. Though spirituality may be

important in some aspects of health²²⁸ and while a doctor may also be a religious leader who is well versed in their faith, it is not generally regarded as part of a doctor's social remit to bring their religious role to their medical role and offer the patient religious advice. Nevertheless, a patient may reasonably expect a health practitioner to be a person of virtue²²⁹ and might use this expectation as part of the cognitive process that they employ to find a health carer trustworthy. The patient might judge that one such virtue, is that the doctor has a disposition to respect (or even shares) the patient's spiritual beliefs. Furthermore, a doctor might appropriately mention to a patient of various spiritual beliefs as relevant to the patient's care, but they should not suggest that one spiritual belief is preferable to another. Nor ought a doctor to deceptively conceal (on the basis of the doctor's spiritual beliefs) from a patient standardly available health information. It is not permissible for the doctor, while in that role, to persuade a patient to adopt the doctor's religious convictions as part of the health care that they offer. It would not be difficult to develop an argument for the claim that a doctor proselytising to patients when the patient is vulnerable is a case of manipulating a person to follow a doctor's religious belief (Best, Butow, & Olver, 2016). Indeed, in being aware of the sensitivity of the possible differences between their spiritual beliefs and their role as health carers, doctors might be wary of being too involved in the religious or spiritual domain. In a study of palliative care doctors' beliefs about spiritual care,

“a major barrier was conflict between their beliefs and that of the patients, reporting moral distress when promoting or affirming beliefs that the respondent considered to be untrue and ultimately futile. Because of not wanting to abuse the

²²⁸ Indeed a doctor may acknowledge the importance of spirituality to a patient.

²²⁹ The patient might judge that one such virtue, is that the doctor respects or even shares the patient spiritual beliefs.

position of power, the respondent therefore generally avoided the issue other than facilitating access to relevant religious leaders” (Best et al., 2016, p. 3302).

That is, doctors for fear of “abusing their position of power”, would not enter into dialogue with their patients over views of the patient that the doctors thought were ill founded based on the patient’s religious beliefs.

In all the three types of relationship discussed above – friend, spiritual advisor, or health carer – there can be the giving or sharing of objects of hope. Examples of objects of hope being given, are to not be alone or to in some way to have a special relationship with the other. In health care the patient might hope to not be isolated and alone in their illness, and to maintain a special relationship with the other. The promise the doctor ought to keep is that she/he will endeavour to maintain care and not leave the patient. Such a promise, if genuine, provides a patient with a genuine object of hope. A further promise of doctor to patient is that the special relationship is predominantly for the patient’s health, not for the doctor’s own personal interests. In health care, the “special relationship” is the offering of emotional warmth with compassion and respect. I conclude that compassionate care commonly involves helping people overcome or avert obstacles to health to avert despair. Doctors owe it to their patients to be compassionate in their care and to effectively help a patient to avert despair. Even where there is no foreseeable effective treatment or cure, a doctor owes a patient compassionate care by assisting a patient to find well-grounded objects of hope, such as a doctor’s promise to care for the patient, rather than misguided objects of hope.

4.7 If hope is a therapeutic tool of health care, doctors owe it to patients to ensure that the patient is informed of this and such hope ought to be well grounded.

In this section I discuss how cultivating hope is widely thought to be an important part of a health carer's role, however importantly for this chapter, I support arguments that to care for patients' hope requires, both conceptually and morally the carer to care how the patient hopes and to be open about the use of hope. A plausible conceptual claim about caring about hope is that, "To care for the hopes and hopeful agency of others is thus to care about the clarity with which they pursue their own hopes while endorsing the value of their own hopeful activities as such" (McGeer, 2008, p. 123). Building on this suggestion care for others requires being clear about how those being cared for acquire and go about attaining the object of their health-related hopes. While remaining respectful to the patient and what they hope for, an ethical health carer ought to encourage a patient to form health care related hopes in ways that are well founded and can be discussed with others rather than form hopes in ways that shun deliberation and ignore outright manifestly plausible evidence.

In the past centuries, physicians offered many ineffective and harmful cures and in addition to this, they offered patient grounds for considerable hope without necessarily attending to the nature of the hope nor to its derivation. "Always give the patient hope, even when death seems at hand" wrote Ambroise Pare in the 16th Century (Ruddick, 1999, p. 343). Further, I quote from the first code of ethics of the American Medical Association (1847) stated that, "For the physician should be the minister of hope and comfort to the sick; that, by such cordials to the drooping spirit,

he may smooth the bed of death, revive expiring life, and counteract the depressing influence of those maladies” (Coulehan, 2011, p. 155).

While health carers of the 20th century arguably had less community standing than their counterparts of the past (Imber, 2008), a much repeated observation is made that there is something therapeutic about “seeing the doctor” and that hope is therapeutic. Indeed, some authors make the strong claim that doctors must *always* in some sense provide hope. An example of such a claim is, “Most importantly, no patient should ever leave a visit with a physician without a sense of hope” (Harris & DeAngelis, 2008, p. 2920). Encouraging hope is still seen by some as part of a duty of care to aid health, “Although it is common sense that hope is a fundamental element of overcoming any illness, the clinician’s role in encouraging hope has been framed as one of the distinctive elements of the “art of medicine,” (Bressan, Iacoponi, Candido de Assis, & Shergill, 2017, p. 1). While I have argued that health practitioners have an important role in fostering grounds for a narrow form of hope in health care which pertains to that which is well founded and well informed, it is not clear that hope is a part of overcoming “any illness”. I wish to clarify what type of hope carers ought to support.

In short, while health carers may be justified in openly making use of hope in a qualified way in assisting patients to cope with for example cancer, health carers ought not to foster in their patients the belief that hope itself might cure cancer. Though hope might improve important quality of life aspects of patient, a practitioner does not have scientific evidence that hope has direct impact on organic disease. Hope might impact psychological states, that in turn might impact on how a patient seeks out and undergoes treatment, as can be seen in the following.

- (Schofield et al., 2016) This study reports that measures of depression are

inversely correlated with survival from advanced colorectal cancer and that as hope measurements have strong negative correlation with depression scores,²³⁰ hope may have therapeutic effect, though no direct effect is shown. That is, treating depression has direct effects on survival in this group, and patients in this group who feel more hopeless have more depression.

- (Ringdal 1995) Showed that “hopelessness was not significantly related to survival when other covariates were controlled for”

- (Petticrew, Bell et al. 2002) Showed from a systemic review of 26 studies “there is little consistent evidence that psychological coping styles play an important part in the survival from or recurrence of cancer” Many of these studies included hopelessness that was construed by authors to be part of a coping style.

Some have argued that loss of hope that occurs in and apart from depression in palliative care settings, (Breitbart et al., 2000) might directly adversely affect clinical outcomes in the way that depression with its loss of sleep, disrupted circadian rhythms and motivation, reduces a patient's ability to seek out healthy outcomes or find effective care. Indeed, uncontrovertibly carers ought to be available to assist patients with depression, however it would be a contentious further step to say that treating depression justifies carers colluding with a patient's false/misguided grounds for hope. Deceiving a depressed patient, “to maintain their hope” in a hope that is highly improbable where there are foreseeably probable hopes is still deception, even if well intended, and may deter the patient from finding new more well-founded grounds for hope and lead to a sense of betrayal. Furthermore, such deception contravenes what doctors and patient owe each-other in a fallibilist relationship based on mutual respect and honest co- deliberation.

²³⁰ Hopeless is one of the symptoms of depression(American Psychiatric Association, 2013).

Even if hope is not proven to have direct therapeutic effects, the therapeutic relationship itself often has therapeutic effects (Brien, Lachance, Prescott, McDermott, & Lewith, 2011), as (debatably) might the placebo effect (Kienle & Kiene, 1997; Shapiro, 1997). Brien's study shows evidence that the therapeutic effect of homeopathy is based in the relationship, not in the homeopathic prescription. If this study's conclusions are credible, the object of a patient's hope in homeopathy, is based on the strength of the relationship, not from the remedy they are prescribed. The remedy is merely a means of maintaining the relationship. In such a homeopathic consultation, a carer and patient ought to be transparent that the patient's object of hope comes from the caring relationship, not the homeopathic remedy. A practitioner might counter that indeed care may justifiably be based on placebo or a so-called inert therapy with the following steps - and though I will not here challenge steps 1 and 2 due to constraints of this project's word count, I will argue that step 3 does not follow logically from steps 1 and 2.

1 Setting oneself up as a health care authority and giving care has in and of itself a therapeutic effect.(Brien et al., 2011)

2 The therapeutic relationship is especially effective if one shows care and *seems* to "give hope".

3 If there is a therapeutic effect in being an authority figure, and no physical harm is being done, then "giving hope" by being authoritative justifies doing so. ²³¹

On this argument, with so many ailments that elude E.B.M. based treatments (Gray, 2017), people with such ailments are nevertheless entitled to care and deserve the

²³¹ Such an argument is mentioned in the last chapter, referring to a quote from Hansen(Hansen, 2012). Though anecdotes are not verifiable evidence, I have heard this argument given at acupuncture meetings of the medical association of acupuncture that I trained with.

choice to acquire grounds for health care related hope from some other source if they feel that the process of E.B.M. is giving them none. A limited account of health care might set health care as firstly doing no harm and secondly focused on averting pain or aiding happiness in the present time. According to such a limited account of health care, good clinical care occurs where a patient feels cared for and leaves the consultation feeling better, if no direct harm is done. Such an account of health care might seem unlikely to be held by people, however I have heard this argument presented to me as an account of “good care” at medical practitioner C.A.M. meetings that I have attended.

From my experience in talking to colleagues at medical practitioner C.A.M. meetings, some doctors change to practicing C.A.M. precisely because the responsibilities involved in such care might have fewer apparent risks. It might seem wonderful to not be exposing the patient to risks of surgery and/or the drugs of conventional medical care, and to know that a type of care is being provided and that the patient feels well after receiving this type of care. However, the perceived low apparent risk of a therapy in no way confers credibility for a therapy. An apparently low risk of a therapy is not sufficient evidence that a therapy ought to be used in patient care as plausibly other considerations ought to be considered, such as the therapy’s efficacy in achieving some health outcome. What is perceived as “safe” by the carer and the patient may be on one level inert, like a homeopathic remedy, however it might have foreseeable harms, for example by a patient deferring plausible and available effective care. A therapy based on placebo offers fewer effective therapeutic options to a patient for many diseases compared to effective therapies derived from E.B.M. processes. Furthermore, to lack a broad experience and knowledge of E.B.M. processes and evidence limits the holistic model of health care that a practitioner can offer. With

empathy *and* compassion, an oncologist can offer as many options for objects of hope as might any other practitioner. An oncologist can *also* offer broader holistic and more effective care because they have more therapeutic options and usually work in a multidisciplinary team with many other health professionals. From my experience as a clinician, practitioners who try to use E.B.M. processes are familiar with feeling that in cases where there are no clear treatments, or where the illness is self- limiting, they must “do something” due to pressure from the patient, the patient’s family or the clinician’s desires to offer a cure. If the doctor does nothing, they might be seen as “not to give hope”²³², and again if one does no harm, why not go ahead and “do something”?

Perhaps for this reason clinicians resort to placebo as they believe that a placebo might bring an object of hope for patient. However, as I have argued, it is not clear that a doctor can or “must (always) give hope” (Ruddick, 1999, p. 343). Additionally, in cases of placebos, where the carer hides from the patient the true nature of the sham treatment, these can be construed as being deceptive treatment, even if prescribed for “the patient’s good or to maintain the patient’s hope”.

For example, suppose that I am administering acupuncture to an elderly, lonely woman, ostensibly for her aching joints or alternatively, that I am giving her regular low dose, safe, Vitamin B12 injections as a “tonic”. If I know that her consultation with me amounts to a social outing for her and a focus or object of hope for her week, then am I engaging in mutual deception by treating her with acupuncture or giving a tonic or even just having a “check-up”?²³³ This is deceptive treatment, unless we are both

²³² This expression. “to give hope” might be commonly used, as compared to what I claim is a more precise expression, “give objects of hope.”

²³³ GPs recognise that in many medical consultations there is a presenting complaint that may be a cover for the real reason the patient presents, often mentioned as a “by the way” at the end of the consultation. (Neighbour, 2005) That is to say a patient may seek care or the doctor’s consultation for “non- medical” reasons.

clear that the principal reason for giving the B12 or to “have a check-up” is for the supposed therapeutic effects of the relationship. Open placebo may seem less ethically problematic if all parties are aware that the purported therapy is merely an excuse for a social visit and the sham treatment is just a gate way that both parties tacitly agree not to discuss as they seek the therapeutic relationship. In such cases the basis of hope of care being offered is company of a professional or person, not the therapy itself. Citing Brien’s paper as evidence; the “relationship” is the active therapeutic ingredient of care, not the check-up or the remedy. It is unethical for a practitioner to represent themselves as having some special authority that a patient owes a duty of listening to if the basis of the relationship is the deceptive use of placebo. The carer has a duty to the patient to clarify that the efficacy of the therapy is the power in simple the practitioner’s company or placebo, not the declared remedy. Nor ought a carer feel that they have a duty to the patient to give objects of hope, where the objects of hope are based on some deception, where it would be more respectful to the patient to be honest in saying that the relationship was the basis of care.

4.8 Examples to illustrate the ethics of well-founded, informed hope in health care that is based on the schema of the three linked constructs.

In this section I use examples to illustrate my arguments that in health care, expert carers have a special duty to appreciate the differing types of hope and the ways in which hope may be used for positive or negative ends in health care. I use one example to illustrate the argument that compassionate carers have a duty to assist patients when the patient is on a path to ill-founded or misinformed hope in health matters. In the second example the patient gives more credence to a belief than his

carers do and I discuss what the carers owe to the patient, where there is disagreement about the significances of the probability of a cure. The nub of this section of the thesis is to highlight the nature of disagreement about interpretation of evidence between the patients I discuss; Dan and George, and their carers. My aim is to develop a framework for how (and in what circumstances) carers ought to help a patient to find what they can see are new well-founded grounds for hope when the patient sees none or hopes for something that might foreseeably never occur, where they have discounted well-founded grounds for effective care that is derived from the process of E.B.M.

Rather than use cases from my clinical experience that have provided the motivation for this thesis, I borrow from Jerome Groopman's work, *"The Anatomy of Hope"* (2004), which, among other things, examines how people prevail in the face of illness. These examples are similar to clinical encounters I have seen as a doctor. In one case, carers attempt to show a patient probable grounds for hope where the patient falsely believe there is none and despairs, refusing effective care. In another case I discuss who may determine what "well- grounded hope" is, and importantly for my thesis I argue that "rights to hope" might impact on others to whom respect is due.

The first example involves Dan, a Vietnam veteran, who is admitted to hospital with an aggressive lymphoma that fills his chest, rapidly blocking his lungs and major vessels. Dan refuses chemotherapy, saying that there is no use in pursuing treatment as he "knows" he will die, based on his intimate understanding of death gained from Vietnam combat experience. In short, he has a "premonition" that he will die.

Doctors and nurses try to work out what psychological processes are blocking Dan's acceptance of effective care, and finally his wife indicates to Dan's carers that Dan saw his fellow platoon member die from lung cancer in terrible pain in an intensive

care unit after months of what seemed to be cruel chemotherapy. To Dan there was no point in resisting death because he had seen so many die in Vietnam, and more recently had witnessed his friend's death.

Finally, Dr Groopman persuaded Dan to accept treatment “one step at a time”, and if Dan wanted to stop then his wishes would be respected- that is, the patient was in control at all times. Despite some setbacks, the tumour regressed and Dan remained well 10 years later.

A second example is illustrative of the previous discussion on credence as relevant to what an individual attributes as acceptable grounds for their hope. The differences between possible, impossible, probable (McMillan et al., 2014) or improbable grounds for hope is highlighted by the case of Dr George who was a colleague of Groopman's, and a pathologist with world-renowned expertise in stomach cancer, who contracted a usually fatal stomach cancer. Against the advice of all his colleagues, Dr George opted for radiotherapy and chemotherapy, followed by massive surgery. Groopman's case informs us that the reasons Dr George gave such strong credence to the 1 % probability chance of cure were due to his strong belief (A) in the sanctity of life, so any chance of life was a chance worth taking and (B) that he was from, “strong fighting stock” and that “if any- one was going be the lucky one to be successful with that 1 % chance , it was him” ²³⁴. He suffered the complications of this radical therapy and was not expected to survive the many stages of his chosen treatment, but he came to be numbered among the 1% who survive this type of cancer. Groopman's salient point in recounting this case was that Dr George had a "right to hope"(Groopman, 2004, p. 58) for a cure, and Groopman argued that Dr Georges' colleagues could not take that away from him, nor could they justifiably refuse him the treatment he requested.

²³⁴ These are my words to paraphrase the author's representation of the case.

Groopman wrote in this context, "It is part of the human spirit to endure and give a miracle a chance to happen" (Groopman, 2004, p. 58), which has links to previously discussed "radical hope" or Marcel's concept of "Hope against hope" (Marcel, 1951b). However, in George's case, there was a 1 % chance of success. I am interested in discussing what a "right to hope" might refer to, particularly with impossible or highly improbable objects of hope where there are more probable objects of hope readily available to a patient. I will first discuss how different people may give differing credence to the grounds for objects of hope, than turn to discuss the "right to hope"

In the first case, Dan's case, we have an example of a medical team attempting to persuade a patient to accept treatment. The medical team suspected that some subliminal factor/s (unknown to Dan and the medical team) were blocking Dan from seeing what the team counted as a credible treatment. The medical team considered Dan had a plausible chance of survival where Dan thought he had none. The carers gave ethical care by not abandoning Dan to his cognitive biases²³⁵ and salience setting feelings of choking²³⁶ that lead him to ill- founded despair. Dan's carers genuinely strove to understand Dan as a unique person and helped Dan to understand biases that he had not been aware of. Finally, with Dan's wife's assistance, the blocking factors were found, and Dan was empowered from despair to take up the team's suggestions. Dan was shown information that his biases that had blocked him from considering, that led him to change what he could conceive to be possible hopes. In this manner, Dan's health practitioners were exemplars of how practitioners ought to attend to what and how a patient hopes for where in the schema of the three associations, both patient and practitioners respectfully ought to attend to each other's

²³⁵ Cognitive biases are discussed in section 5.8

²³⁶ The choking feelings were due to the lymphoma compressing structures in his chest.

representations of their values and beliefs as relevant to the patient's health care.

Groopman also points to another element that influences what forms of hope might avert despair- that is, biological processes in ill people such as various hormones that are released in illness, and/or as physical sensations occur (e.g. choking feelings in Dan's case). Plausibly, we widely believe that hormones or chemicals may affect how we think (Groopman, 2004). For example we see the effects on people's behavioural patterns from extremely low glucose levels, or from changes to sex steroid hormones, or from the oxytocin effects on empathy (Barraza & Zak, 2009; Shamay-Tsoory et al., 2013). For eons humans have taken chemicals to induce altered states of feeling and/or cognition. For example, the use of amphetamines, alcohol or opiates demonstrates the effects of chemicals on how we feel and think. Plato argued that some feelings can be false, if the senses that lead to such feelings are delusional, or if a feeling is both one feeling and what it is not, at the same time. For example, a glutton who over-eats for pleasure, while at the same feels displeasure for their abdominal pain and remorse for overindulging, has no pleasure at all as they eat more food. Possibly Dan's despair was a false emotion (in this sense), as his senses might have deceived him that he was choking when he was not. If this was the case, Dan's carers were right to believe his despair was "false" (in that sense). Hope is both cognitive and affective. Dan's carers had a duty of care to respectfully offer Dan grounds for hope, as objects of hope of hope in health care ought to be based on well-grounded beliefs, and a genuine emotion of hope that Dan came to feel once his senses accurately represented his surroundings.

In my view Dan's case is an instance where a medical team may justifiably argue that there was hope where the patient saw none, and that it was part of their duty of care to the patient to show Dan grounds for such hope. To show care for Dan the

carers were obliged to care about how Dan came to *not* have hope.²³⁷ Importantly for the doctor-patient relationship, respect for others and part of what we owe each other may be to care for what others hope for and how they come to hope, or not hope and subsequently despair.

John Stuart Mill's (Mill, 2011) example of a person walking across the bridge, in which an observant bystander has an obligation to warn that person that the bridge is incomplete, comes to mind here. Mill claims that it may be justifiable for a bystander to stop a person and warn them of danger, but Mill argues that it is not justifiable for the bystander to altogether prevent the person from crossing the bridge, once the person is appraised of the facts about the bridge being incomplete, as only the person knows the value of his/her life. Similarly, if following Mill's approach, the health team noted an alternative path forward that Dan could not see, their duty was to then attempt to persuade Dan to see that path. We may have agreed with Dan that only he could know what he may have hoped for, but we may have justifiably made him aware of elements that might have been important to the reasons that lead him to hope in a certain way, or indeed to lose hope.

In Dan's case, his decision-making faculties were impaired, and his health carers had a right and an obligation due to their duty of care to try to show Dan the justifications for their sense of hope. Dan's beliefs that his death was inevitable were ill-founded, as his friend died from a lung cancer, which is a very different cancer to lymphoma. Dan did not know that all cancers are not the same, and that his lymphoma was curable. Dan's body gave out neuroendocrine stimuli that led to a feeling of choking that Dan believed was further evidence he was dying. Dan's interests were

²³⁷ In section 4.7 I quoted Victoria McGeer arguing that carers ought to care for how a patient hopes, I further more argue that carers additionally ought to care about how patients are misguided in not seeing well-founded grounds for hope.

best served by appraising evidence that his carers tried to show him and his survival depended on him giving less credence to feelings of choking (induced by hormones) that made him feel and believe that there was no hope. Here is an example where what one feels corroborates misguided beliefs and is not an accurate representation of the “facts” of the situation, as seen by carers and as vindicated by the outcome. Phenomenological processes might be powerful and might be salience-setting, however, I support arguments that a person is wise to attempt to understand the basis of what they feel and be reactive to deliberative processes that temper phenomenological processes, and additionally, not ignore all of their feelings when making more deliberative judgements.

In Dan’s case, the practitioners didn’t seek to give him grounds for hope based on their unique worldview, but acted to recommend treatment options that, though then new, had been tried successfully around the world. It was not a case of Dan liking his health carers or thinking his health carers believed in the same things he did. The carers did not specifically seek particularly Dan’s trust in them as individuals but sought for him to trust enough to at least consider the evidence they provided him that the treatment would work. The new medications to shrink the aggressive lymphoma did not need the doctors’ personalities to make them effective. Nor did the drugs require Dan’s faith in them to work, as they were effective in their own right. So in this setting, persuading Dan to see well-founded grounds for hope in the new standard lymphoma drugs, had no (or minimal) intrinsic therapeutic effect but was an adjunctive to the informed consent process.

I now turn to the case of Dr George through which a question may arise as to whether a doctor has any business in questioning what hopes a patient has, even if the doctor thinks that such hopes are based on remote possibilities or falsehoods. Salient to this

question is the difference between what a person *might* not and *ought* not to hope for, what credence a patient gives to grounds of what they hope for and what a carer ought to do when they see a patient following a foreseeably misguided hope on a trajectory to harm.

For reason of concern for the patients' interests, a carer ought to question a patient when the patient's hopes are grounded on what is plausibly considered to be false or impossible, even though the patient has genuine, but misguided hope. In the ideal schema of the three associated constructs, each party is open to and respectful of other party in co-deliberating beliefs and values as relevant to health care. If a carer believes that a patient is about to be harmed by something that the patient ought to be aware of, if we are to be guided by the example of J.S. Mill in the previous pages, the carer ought to help a patient become aware of that danger. In the schema, a patient owes it to their justifiably trusted carer to listen to why the carer thinks that an object of hope is impossible to achieve, as a patient ought to acknowledge that (a) the basis of their doctor's care is to act in the patient's interests, and so the doctor must have reasons to invite dialogue about a certain belief and (b) a patient ought to be aware that a doctor feels an obligation to care about what the patient hopes for and how they come to have that hope. Furthermore, a patient has obligations to consider dangers or alternative paths that the doctor foresees, for if a patient takes a foreseeably lethal path, others including their doctor and family might suffer.

A patient might claim that they have a right to hope for almost "anything" rather than "nothing". A scenario may occur where patients have been informed by E.B.M. processes that there are no known treatments for a condition, and so patients try a novel ill-founded therapy as they have "nothing to lose"- and even when the patient is

sceptical about the efficacy of the treatment, but says “who knows, it may work, as there may be a miracle”. This argument is appealing to the uncertainty requirement of hope, in that in hoping for something, we can never be absolutely sure what may occur. However a key difference in the case of Dr George is that he is seeking treatment that processes of E.B.M. suggest might have a 1 % chance of cure for the people studied, rather than trying an untried therapy where the percentage chance of cure is unknown and is highly implausible. In being informed that his chance of cure is 1% by using processes of E.B.M., Dr George was not trying a treatment believing that he has nothing to lose, he was hoping for the 1% cure. In one case the patient is informed as to their chances based on what occurred to other patients in the other case the patient has no evidence to be informed by, other than perhaps their optimism that an implausible treatment might work. The colleagues administer the treatment George asks of them, even though they think it is *likely* futile, as they realise that we know so little of the human body and disease, and that there is so much variation in the individual case, they are obliged to help Dr George take his 1 % chance, (assuming no debate over access to resources) and respect his way of assessing credence in this matter. In this case no one is offering much probabilistic (grounds for) hope of cure, and there is no consequent deception. However, the 1 % chance is not evidence of *no* plausible object of hope, and even such a low chance may be a basis for genuine hope when there is no foreseeable alternative.

In the accounts of the process of E.B.M. that I discussed those who refer to them are guided to recognise that each person may attach differing value to risk, and that beliefs may have differing value to different people as evidence by including the patient's perspective. A 1% chance of success is not fantasy but is a possibility of success even if remote and may have differing significance to each patient depending on their

circumstances. If the value of life²³⁸ is great and the value of fighting for life is great, a 1% chance is a chance many think is worth fighting for. Such consideration of risk can be seen in paediatric oncology as described in the following, “Parents choose options with infinitesimal odds [of saving their child’s life] because the prize they sought was of immeasurable worth” (Bluebond-Langner, Belasco, Goldman, & Belasco, 2007, p. 2417). In conventional oncology, treatments are used if there is a remote, even 1% chance of success. In support of this claim, Bluebond-langer writes that, “For a disease-directed option to be worth trying, all that was required was that the oncologist not declare that the possibility of some change was absolutely zero” (Bluebond-Langner et al., 2007, p. 2418). I have argued that hope based on a low probability of attainment can be genuine hope even if not probable that the hoper will attain the object of that hope. Informed and well- founded hope in the context of health care might sometimes be improbable but is at least possible.

For George that 1% was a possible basis for hope, even though such hope was shared more hesitantly by his treating colleagues. George’s doctors might have been concerned for George that they would cause him great suffering through the treatments that they gave George. However, George was prepared to accept great suffering for his 1 % chance of survival. The hope to survive and overcome the cancer was George’s to have and not his doctors, and out of respect for George as an individual who had his own way of attaching value to evidence the doctors assisted George with the treatment that they informed him of. Mutual respect and co-deliberation which are so key to the three linked constructs of the schema, saw George get support from his carers and prevail through onerous, most uncertain treatment.

²³⁸ That there may be a “value of life” is a contentious notion but put simply without further discussion, I hold that an amoeba’s life has a different value to that of a human person’s life!

Though the treatment was uncertain, at least there was some evidence of its possible chance of success as opposed to no available evidence. Mc Millan further claims that even without sufficient evidence to make an estimate of an outcome a person can still hope for something based on “general considerations”. However, I am unclear what such considerations might be.

A possibility hope is a hope for an outcome when there is insufficient evidence on which to base a reasonable estimate of the likelihood of that outcome, but that from general considerations it is at least a possible (though perhaps unlikely) outcome.” (McMillan et al., 2014, p. 37).

In contrast to George’s case, in the case of a patient trying an ill-founded and untried possible treatment (where evidence of success is not known) because the patient believes that they have nothing to lose- this seems to be almost a reckless choice. It is hard to see the object of hope being “foreseen as attainable” in such a choice. Nor is there the element of arduous effort, to get to an object of hope, but a feeling of passive resignation that one vaguely expects that a course of action will get one to the desired goal (but one does not really expect it). In the “nothing to lose case” outlined above, it seems that co-deliberation may be less thorough or indeed bypassed. A person with end stage cancer may try a novel untested therapy at the flip of a coin, as there is nothing to lose, and they may choose whatever option the coin lands on. My point here is that it is difficult to hope for success with much conviction in such a scenario, as such hope is anything but “arduous of attainment. Furthermore, in such an extreme case a patient might feel that they may make a reckless choice “as they have nothing to lose”, and while this may or may not be the case for them, there might be a lot to lose for their loved ones, or their doctor. The patient’s loved ones or doctor might not feel that the patient has nothing to lose as they do not want to lose the patient

due to some reckless decision to follow an ill-founded unjustified object of hope. In a relationship where all parties have agreed to respect each other by attending to one another, the loved ones and doctor may ask the patient to consider that they are not “nothing” of the patient’s “nothing to lose”.

A patient ought to consider what they believe they have a right to hope for, as they have a special relationship with their carer that the patient ought to be aware is premised on the carer having a social remit to act in their patients’ best interest and what the patient hopes for. As discussed, part of a practitioner’s role in providing health care is to assist a patient to have the chance for informed hope, as the carer ought to care about what a patient hopes for and how the patient is informed of grounds for such hopes. In hoping for something which is in fact impossible to achieve, particularly where better-grounded alternatives are foreseeably attainable, the patient may place upon the carer too great an expectation that might be unfair to the carer. Disrespect might be shown to the carer if the carer’s advice is ignored by the patient outright, as a carer has promised to stay with the patient in a special relationship whereby each person considers the other’s views as worthy of consideration.

A claim might be made that Plenty Coups (in the case of “radical hope”) and Dr George had a “right to hope” in the sense that what they hoped for was remotely possible, no matter what the reasons were as to why they came to form that hope. In spiritual hope, for example based in part on a belief in ascension to an afterlife, we might claim to have a right to hope for such things, as no one “knows” whether this is possible or not. Evidence of the afterlife is debated by differing spiritual and non-spiritual groups however proof of such an afterlife that all people can agree upon is not currently apparent. Furthermore, a person might have a genuine hope to become superman, which is an impossibility, but still such a hope is genuine in the sense that

hope is an emotion that may be based on ill-founded beliefs. However, the genuine character of a patient's emotion of hope, does not mean that a health practitioner always ought to accommodate what a patient hopes for.

A person's exercise of a right might impinge on the rights of others and may bring about obligations on others that are unfair for others. For example, a tolerant society ought to respect many "rights of religious hopes", and some groups are obliged to curtail some of their activities to respect others. However, we have no obligation to accommodate the right to hope asserted by an aspiring superman if such a "right" might disproportionately encroach upon the rights of others by placing an unfair expectation upon them. Where a patient ought to consider the obligations they have to be respectful to others and consider the impacts on others of their health choices, the patient who is less responsible in how they exercise their "right to hope", might be considered as to some degree blameworthy, for harms they cause to those who are impacted by what they hope for.

A patient may suggest that they have a right to hope for a cancer cure by some alternative practice, but this "hope right" may impinge upon the rights of their spouse, for the years of care that the spouse might then feel obliged to give that might unduly restrict the spouses' freedoms and their former hopes of living with their partner into old age. The wife's' hopes have been enmeshed with her husbands' hopes, for example to raise grandchildren, share a grand caravan trip and to have more time together. Such an example is illustrative of the idea that hope is often relational, in that one person's hopes might impact on what another person hopes. If a husband's hopes for something creates obstacles to what his wife hopes for, the wife might object that his claim of a right to hope for something, impinges on her objects of hope. In the case of Dr George, his right to hope for cure based on a 1 % chance might jeopardize the

rights of others who are deprived of basic medical care due to the resources dedicated to Dr George's potential cure. Dr George ought to appreciate that his carers might feel anguish at causing him great suffering from the treatments they administer, particularly if George dies from one of the treatments. It is not clear that a person always has a right to hope for what they like or believe to be in their interests. What a patient hopes for might unfairly impact on the hopes and interests of others and create undue expectations of carers.

One person might and rightfully may attach a high level of credence to the same probability that another person considers to be trivial. However, though a minimal degree of possibility might support genuine hope, to give ill-founded grounds to an ultimate health hope based on a remote lottery chance where there are effective care options, might be imprudent for the patient. Furthermore, for a patient to accept "lottery or superman hope" in health care decisions and to thereby reject outright carer's attempts at dialogue about plausible or probable objects of hope, might show disrespect to loved ones whose hopes are intertwined with the patient, and may be seen as dismissive of carers who would rightfully feel the weight of duty to support a patient in an environment of informed hope. In an ideal deliberative fallibilist schema of the three linked constructs that may form the doctor-patient relationship, both parties owe it to each other to attend to one another's' views as to what it is possible to hope for in the domain of the patient's health care.

Chapter 5: The ethical use of trust in a fallibilist model of health care.

5.1 Introduction.

In the previous chapters I argued that ethical health care involves co-deliberation and at the least recognition by the patient, and by those close to them²³⁹ of each other's attitudes to and beliefs about health care issues. Now I will argue that ethical health care requires special attention to how such people come to trust their beliefs and that ethical health care requires qualified trust in qualified experts rather than unqualified trust in poorly qualified experts or in ill-founded evidence and beliefs.

I move to define the specific, limited nature of trust that ought to be used in most health care decision making. I discuss the moral implications of trust in health care, and argue that there is a spectrum character to trust with at one end, an extreme kind of trust that is dogmatically held faith that a person is emotionally committed to, and at the other end a more cautious, probationary form of trust that I argue is the foundation for an ethical system of health care based on fallibilism.

5.2 Accounts of trust to be debated.

I initially provide quotes illustrating three accounts of trust that can be usefully compared, for the purposes of this thesis. These accounts of trust that I initially discuss all hold that trust is simply a matter of predicting future events, and construe trust as being a cognitive process of belief formation, more than forming an attitude. I conclude this section by arguing that many forms of trust, in ethical health care, while cognitively guided, are an expectant emotion or attitude. Further I discuss an account of trust,

²³⁹ By "close to them", I mean people such as their family or loves ones and in cases the health practitioner with whom they have a moral relationship.

which is particularly relevant to the doctor-patient relationship, whereby trust may be considered as a kind of tool, used to build relationships and to transfer not only expectations but duties from one person to another. For a doctor or patient to deliberately not fulfil an expectation of the other that is reasonably held towards them, may be a breach of the other's trust.

Some rather minimalist accounts of trust appear to be based on trust being simply a matter of accurate, reliable prediction, "trust (or, symmetrically, distrust) is a particular level of the subjective probability with which an agent assesses that another agent or group of agents will perform a particular action....." (Gambetta, 1988, p. 217). I discuss the merits and problems with this account in the next section.

However other authors have developed arguments for conceptions of trust which hold that it involves far more than merely giving credence to expectations about other/s. For example, Karen Jones argued in her earlier work that,

..trust is an attitude of optimism that the goodwill and competence of another will extend to cover the domain of our interaction with her, together with the expectation that the one trusted will be directly and favourably moved by the thought that we are counting on her (Karen Jones, 1996, p. 4).

Subsequent authors challenged that optimism is always a necessary condition of trust²⁴⁰. Also, at times trust might be more than a private emotion and can be felt by others and can affect others.²⁴¹ Furthermore, the emotion of trust might be held by the one who trusts and have an association with how the one who is entrusted

²⁴⁰ As per section 5.5

²⁴¹ For example, I might keep it private that I trust someone, in that I do not state to them that I trust them, or give them overt hints that I trust them, however my body language or other actions might lead them to believe that I do trust them.

demonstrates that they are trustworthy. Jones described a notion of “three place trustworthiness” where; trustworthiness relates to a trusted person (1) being competent in the domain in which they are entrusted, and that this entrusted person (2) can see that another person feels that they are relying upon them (3) considers that this person’s feeling of reliance on them is a compelling reason for them, the entrusted, to be trustworthy. Jones makes a claim that,

Three-place trustworthiness is not, however, the whole story of trustworthiness. As finite agents, we want more from others than responsiveness to dependency in a domain: we want those who can be trusted to identify themselves so that we can place our trust wisely (Karen Jones, 2012, p. 62)

Jones further describes “rich trustworthiness” “whereby trustworthiness requires that not only the person who trusts signals their emotion to the one they entrust, such trust is recognized and acknowledged by the one who is entrusted.

“B is richly trustworthy with respect to A just in case (i) B is willing and able reliably to signal to A those domains in which B is competent and will take the fact that A is counting on her, were A to do so, to be a compelling reason for acting as counted on and (ii) there are at least some domains in which B will be responsive to the fact of A’s dependency in the manner specified in” (Karen Jones, 2012, p. 74)

This last account of trust and trustworthiness highlights the relational nature of trust and the need for signalling between parties of what is expected of each other and what each of them is capable of. Important work by Baier (Baier, 1986) on the effects of the betrayal of trust, has led others to develop Jones’s initial notions of trust being more than a mere matter of prediction to an affective attitude that is relational, to trust having a functionalist , normative nature, in the way that trust is duty setting. Such a duty

setting nature of trust, exemplified by Walker in the next quote is also seen in Jones's "rich trustworthiness" where B's awareness of A's expectations is thought by B to be a compelling reason to honour A's trust. According to Walker,

[Trust involves] a kind of reliance on others whom we expect (perhaps only implicitly or unreflectively) to behave as relied upon (e.g. in specified ways, in ways that fulfil an assumed standard, or in ways so as to achieve relied-upon outcomes) and to behave that way in the awareness (if only implicit or unreflective) that they are liable to be held responsible for failing to do so or to make reasonable efforts to do so (Walker 2006 p. 80).

I use this latter description of the association between reliance and trust to develop an account of what a doctor and patient might owe to each other. Certainly, this last association of reliance with trust might explain why we expect doctors to live up to certain expectations that they ought to recognise that patients have of them. For a doctor to be trustworthy they ought to recognise that they need to comply with a high standard of professional behaviour and to be motivated to act in the interests of the patient's health care. I will later argue that a patient too might be liable to others for not fulfilling certain standards in relation to considering how their departure from health, or health decisions can affect others.

The literature which attempts to philosophically define trust is extensive, and so what follows is a critical analysis of some of these accounts and what types of trust a doctor and patient should be wary of if they are to consider their obligations to others. The person who accepts a fallibilist attitude can trust a person or belief in a qualified manner as they acknowledge that how and what they trust may be ill- founded and in fact untrustworthy. In the domain of health care where it seems clear that doctors ought

to be careful in how they treat patients as they can err, such caution also ought to extend to doctors being careful in how they come to trust health care practice and beliefs. The process of E.B.M. is a natural fit for cautious, “qualified” approach to trusting health care practices as the E.B.M process (as I argued in chapter 1) is based upon its practitioners having a fallibilist attitude to what they trust as being plausible evidence for health care decision making.

5.3 Trust, belief, and prediction

I will initially discuss claims from Gambetta’s book (1988) that trust is a matter of rationally deciding what to accept is best evidence in predicting that what is expected, will eventuate. Such descriptions of trust being “well-founded” only if founded upon rational grounds seem to almost set up trust as being a type of justified belief.²⁴² But while trust may have an important function in how we come to form beliefs, and trust may be based on beliefs, I will argue that these mechanisms of belief and trust formation may not be always necessary nor sufficient to define what trust itself is. There may be different forms of trust, with other forms of trust based more upon prediction and other forms of trust based upon other factors that I will discuss. Returning to the argument that trust is simply a matter of prediction, let us consider a larger quote from Gambetta,

trust (or, symmetrically, distrust) is a particular level of the subjective probability with which an agent assesses that another agent or group of agents will perform a particular action, When we say we trust someone or that someone is trustworthy,

²⁴² Jones argues that in defence on one of her initial accounts of trust, that it has strength in its lack of evidentiary nature, “Moreover, it is able to do this without taking a stance on evidentialism, or the doctrine that we should not believe anything without sufficient evidence. Since trust is not primarily a belief, it falls outside the scope of the evidentialist thesis”(Karen Jones, 1996, p. 5) Trust is certainly not a justified belief.

we implicitly mean that the probability that he will perform an actionis high enough for us to consider engaging in some form of cooperation with him.....trust is better seen as a threshold point, ..., which can take a number of values suspended between complete distrust (0) and complete trust (1), and which is centred around a mid-point (0.50) of uncertainty. Accordingly, blind trust or distrust represent lexicographic predispositions to assign the extreme values of the probability and maintain them unconditionally over and above the evidence (Gambetta, 1988, p. 217).

But while I argue shortly that such a notion of trust and trustworthiness is incomplete, it has some merit as indeed often trust seems to include expectations for the future, as an agent attempts to make more accurate predictions as to what may be trusted, to do as the person who places their trust, expects. This notion of trust usefully raises the notion of blind trust and distrust as being adopted by an agent based upon grounds that they consider to be so probable that they will not appraise other evidence.

In another account of trust that is more cognitive and relies upon people appraising evidence and giving credence to beliefs, Pamela Hieronymi suggests that 'trusting belief' requires trust that such a belief,

'be supported by reasons that bear on its truth' (Hieronymi, 2008, p. 232) which she describes as "full-fledged trust". Hieronymi supports a cognitivist account of trust continuing that, "Trust is full-fledged only if one believes that the person in question will do the thing in question" (Hieronymi, 2008, p. 227).

For Hieronymi, more plausible forms of "full-fledged" trust have stronger grounds for their justification than do forms of trust that are based on other types of evidence. Another form of evidence to trust someone might be a feeling of obligation that one

ought to trust someone as they are one's child. As I soon discuss, though such trust may be termed "less full-fledged", it is no less a form a trust. Trust may be more or less supported by various sources of evidence. Pettit also argues for a more cognitivist account of the nature of trust;

"Trust materializes reliably among people to the extent that they have beliefs about one another that make trust a sensible attitude to adopt. And trust reliably survives among people to the extent that those beliefs prove to be correct. Trustors identify reasons to trust others and trustees show that those reasons are good reasons.." (Pettit, 1995, p. 202).

Thus for Pettit, trust may flourish when there are "sensible" reasons to form beliefs that are more grounded in plausible evidence of other's trustworthiness (the property of trust).

Like Gambetta and his "blind trust" such accounts as sketched by the quotes from the above three authors suggest that some forms of trust are more based on cognitive processes that involve making predictions and having degrees of belief about the nature of what is trusted.

While later I discuss arguments that trust is not solely about prediction, prediction *is* often an important aspect of trust, in some contexts for trust such as in health care. At times patients and doctors (in seeking ways to determine what they are best to trust in to achieve a health outcome) will and ought to look for measures of reliability that what they might trust will aid a patient in their healthcare. Some predictions as to what might be more reliable might be well- founded and some predictions may be ill-founded. I do not claim that there is a strict means of determining what is well-founded

in each clinical case, however as with my discussion on credence ²⁴³ what is considered as well founded may vary. “Well-founded” forms of trust”²⁴⁴ pertain to trust where the beliefs, institutions or people that may be shown to be trustworthy are trusted by trustors who have referred to evidence that is additional to that person’s less appraised attitudes and takes into account the views of others who have seriously researched an area.

Though processes of prediction and some form of belief may be part of how we come to trust, trust itself is not merely a rational exercise in predicting what may maximise the satisfaction of an agent’s immediate preferences. Perhaps the property of trustworthiness may be truth assessable and be more or less credible (and particularly in hindsight), whereas trust itself is more an attitude a person holds towards others, rather than solely a prediction about the future. As Thomas writes, “Prediction, unlike trust , does not presuppose any awareness on the part of the object of prediction that a prediction has been made about it”. (Flanagan, 1990 p. 240). That is to say, many instances of trust involve a relationship between two individuals whereby one (or both are/) is aware of the trust that is shared between them²⁴⁵. In this manner trust is more than a matter of mere prediction that one individual might have about some matter, but rather often includes a relational aspect whereby there is a level of minimal

²⁴³ Section 2.5.3

²⁴⁴ An account of more well-founded forms of trust is necessary in health care due to the possible vulnerability of a patient, who dogmatically follows beliefs that may lead to great sacrifice. Following one belief in an ideal to an extreme, for example averting use of chemicals and diverting effective care, ahead of ideals of staying alive as a loved family member, may be an example of dogged adherence to one belief in an ideal ahead of all others with possible adverse moral consequence as discussed by Isiah Berlin (Berlin, 1998). It may seem a great wrong, if the ideal that leads to a young patient’s death is based on unreserved trust in a dogmatically held belief, which is betrayed. Unqualified trust, in the sense that such trust is unreserved (in some one’s/thing’s trustworthiness) may lead a person to refused to appraise ideas from other sources other than what they firmly trust due the possible biasing effect of strong commitment. Commitment to an ideal with unreserved trust, such as following a conspiratorial internet anti vaccine group, may sacrifice other (attitudinal) ideals the patient holds dear, or the interests of their loved ones, if eclipsed by unreserved, trust.

²⁴⁵ Such a relationship may be more personal, such as a doctor being aware that they are trusted to care for a patient in various ways, or more distant, as in the case of a politician being aware that many of her constituents trust her to represent their interests and to betray their trust by being corrupt.

recognition that one individual considers the other in a special way. In this manner trust is associated with “recognition respect” (Darwall, 1977). The trustor and the entrusted recognise, even on a minimal level, that one person holds an attitude to the other and therefore considers the other. Showing distrust towards another person might show disrespect and might also disappoint that person if they had thought that they were trusted. Such relationships of trust may be more personal, such as a doctor being aware that they are trusted to care for a patient in various ways, or be more distant, as in the case of a politician being aware that her constituents trust her to represent their interests and to not betray their trust by being corrupt.

Further argument against the position that trust is always just exclusively a form of prediction-based belief is given by Holton (Holton, 1994) using the scenario of trusting people to catch one, as one falls back in a game in a drama class, without being committed to the belief that one will be caught. Though prediction may be important in some types of trust, as this example reminds us, it may be less important in other forms of trust. Holton’s cases might be considered to be unusual, but they nevertheless serve to illuminate that there might be differing kinds of trust, with some having less basis in accuracy of prediction. Holton gives arguments that we may trust we will be caught, without believing that our drama colleague will catch us, as we seek to show our colleagues that we value trust, or to show the group that we value the individuals of that group by showing them trust. In trusting someone we adopt a special attitude, or as Holton writes, the “participant stance” towards the other person. Holton draws²⁴⁶ on work of Peter Strawson who discussed how the nature of our “reactive attitudes” towards others might illuminate the importance of how we feel when

²⁴⁶ Holton draws on page 5 of the last citation at the start of this paragraph.

someone betrays us. Karen Jones in her chapter titled “Distrusting the Trustworthy” represents Strawson’s position on reactive attitudes as, “those attitudes that we take towards people when we view them from the participant stance, as fellow agents who can be held accountable for what they do”(K. Jones, 2013, p. 188). On Strawson’s account, we feel such reactive attitudes as we are concerned about the others person’s good will towards us. In brief, Strawson described a “participant attitude” whereby people have emotional reaction to others and are claimed to be responsible for their actions as compared to an “objective attitude” that is causally influenced by a person’s environment. Holton calls a participant attitude a participant stance. Holton provides a further example in the moral domain of trust, of a shop owner realizing that they have employed a person who has convictions for petty theft. The shop owner might nevertheless have an attitude of trust towards the employee, not because they believe the employee is trustworthy, but because they feel that they owe it to their employees (as a duty) to trust them as a sign of respect; or that they ought to trust this employee as a way of rehabilitating them back to the community. In these ways we may place trust in individuals when it might not necessarily be plausible to do so. In so doing we can place our (at times qualified) trust without making predictions that are based solely on expectations about a particular declared expectation, rather than what indirect effect our trust might have on the other person.

Does my decision to trust the others entail that I believe that they will catch me? If it does, does this in turn mean that when I decide to trust them, I also decide to believe that they will catch me? I think not. In order to trust I do not need to believe. (Holton, 1994, p. 63)

Holton does not argue that trust may involve no belief at any time. To claim that trust may arise with no belief may be too broad a claim because while a “trustor” (person who trusts) may not believe that nor have optimism in what/whom they trust will act as expected, the trustor might nevertheless believe that the consequences of their trust could facilitate other expectations held by the trustor. Belief may reside not in what is entrusted, but in some consequence of a stance of trust. Holton’s examples might not be examples of what Hieronymi calls “full-fledged trust”²⁴⁷ where what is trusted is particularly sensible or plausible in some respects. However, such “special trust” may be genuine trust even if not “full-fledged” and indeed there may be cases where it is important for our ethical relationships that a trustor’s emotion of trust helps to influence the one who is entrusted to become a person who is plausibly trustworthy. I conclude that trust has a relation to prediction, but not always in a direct sense where a person makes probabilistic calculations about an expectation being realised. Trust may involve predictions of a differing type; that a person is in some way able to become more worthy of one’s trust. A trustor might predict that their trust might help to influence the entrusted person to be more reliable in other ways not currently expected or that they will be positively influenced by being trusted. Such a prediction might be based upon very low expectations of success or a trustor might trust because they feel they ought to trust someone. The predictive aspect of trust needs to be considered in the context of the doctor-patient relationship. In many aspects of health care, if doctors and patients are to base their relationship on a patient centre approach, it might be considered inappropriate for a patient to trust their doctor as they feel they ought trust their doctor, for example, solely because the doctor has the title of Professor and their

²⁴⁷ Such trust is construed as being where a person’s belief can ‘be supported by reasons that bear on its truth’. This quote is from Pamela Hieronymi at the start of this section 5.3

husband says that they ought to trust such an authority. Indeed, it might be the case that some people believe that a Professor might be more reliable in assisting them to achieve a healthcare expectation than a doctor with a different title. However, the predictive element in the formation of their trust is less apparent if a patient were to trust the doctor as they believe they ought to trust authority.

5.4 Trust, reliance and attitude

Authors have argued that the attitudinal nature of trust differentiates trust from reliance and that though both may be linked they are not one and the same. In the literature on trust, the existence of betrayal that may occur when what a person trusts in betrays them, may evoke a sentiment stronger than simple disappointment that may ensue when something fails that one predicted one could rely on. When an inanimate object that an agent relied upon fails, it seems unlikely that the person will be as emotionally hurt by such failure as when an entrusted person or institution betrays them, by betraying their trust. This is not to claim that reliance is not linked to trust but that there is more to trust than mere reliance alone. Annette Baier (Baier, 1986) highlighted betrayal as being a factor which shows that any definition of trust requires (in addition to reasons to trust) interpreting trust as in part an attitude and the acknowledgement of the relational component of trust. I will discuss in the upcoming section on the effects of trust that it is plausible that if a person feels that they have been betrayed, they may adopt an attitude to the one who they felt betrayed them that has impacts on their relationship.

A trustor holds an attitude of trust in whom or what they trust, for trust seems to be more than just reliance. (Baier, 1986) (Karen Jones, 1996). Baier highlighted that though reliance and trust are in many cases strongly associated with one another they

are not one and the same. I may feel let down if a tool I relied upon fails me, but I may not feel betrayed as when I am let down by a person I trusted (Macintosh, 2016, p. 23) To illustrate this point further from another source, “The comedian, the advertiser, the blackmailer, the kidnapper-extortioner, and the terrorist” (Baier, 1986, pp. 234-235) *rely* on those they engage with to act as the comedian, or the advertiser hopes or expects “victims” will, but does not *trust* those they engage with, to purchase their product, be terrified or laugh. Those whose aim is to manipulate people in certain ways, do so expecting their “targets” to behave according to supposed weaknesses, vulnerabilities or heuristics, that the manipulator appeals to. Jones and Baier argue that the character of expectation of “good will” is lacking in such instances of reliance and the presence of optimism of good will of the trustor towards the one that they entrust, is a hallmark of trust. Baier claims that good will is basic property of trust that people attribute to others at a very early age and that,

The persistent human adult tendency to profess trust in a creator-God can also be seen as an infantile residue of this crucial innate readiness of infants to initially impute goodwill to the powerful persons on whom they depend.(Baier, 1986, p. 242)

I am not aware of social research that supports Baier’s claim. Furthermore, suggesting that as she calls it “religious trust” may be tolerated as it is such a “basic human tendency” also, as she points out, is a claim that has not been researched. However, her claim is useful in highlighting that good will might be important in at least some kinds of trust. Jones and Baier, argue (to be discussed on the next page) that trust may be contrasted with reliance alone. In cases of trust, often the trustor believes that the entrusted has good will towards them, whereas in reliance such good will is not

necessary so much as believing that something will perform in a predicted way.²⁴⁸

According to Jones's account quoted above; in coming to trust some- one, I may rely on them not just to perform a function for me, as may a tool or machine, but I rely on them to recognise that I trust them to possess certain virtues that I assume of them and to be well disposed towards me. In addition to recognising my trust, I rely on whom or what (e.g., an institution) I trust to inform me if they are or are not "up to the task" of being trusted. In situations of interpersonal trust, (as opposed to for example, institutional trust) my attitude of trust may feel vindicated when I have evidence from others or from the entrusted, that whom or what I trust is trustworthy; as they are plausibly regarded as reliable, virtuous and qualified.(O'Neill, 2002). O'Neill does not claim that trust is these last three things, but she claims that a perception of these properties in a person might be supportive of that person giving an impression of being trustworthy. We cannot expect virtue of a machine that we rely upon.

Though a patient may reasonably expect to rely upon their doctor in certain ways, we expect that a patient also has a certain attitude to the doctor and that they do not consider that the doctor is a mere instrument for their purposes. The doctor also may reasonably expect to in some way rely upon the patient to engage with the doctor in the process of patient centred health care that is the basis of the relationship. In the ID.D.P.R., trust works both ways in that both the doctor and the patient on some levels rely upon each other but have certain attitudes towards one another. In the context of professional relationship such attitude ought to be qualified within certain boundaries to maintain trust.

²⁴⁸ For counter arguments that expectation of good will is required of trust see section 5.6 on "therapeutic trust".

5.5 Trust and optimism

As Jones reports, authors have argued that trust is an attitudinal state that is based on reasons and emotions (Karen Jones, 1996) that is optimistic towards others and beliefs. However, though optimism may be found in many forms of trust, this is not always the case as trust can also be founded on pessimism about what is expected of the entrusted- for example when Holton's shop keeper realizes that they have hired a petty criminal. Optimism in situations of trust may exist on a spectrum. I will argue that in the clinical context such optimism ought to be reserved ²⁴⁹ while mindful of fallibilism in health care.

Optimism may be integral to most forms of trust but is not limitless in its character as it applies to trust. To quote Jones,

..except perhaps with our most trusted intimates, the optimism we bear is seldom global. This is not to say that the optimism itself is qualified and instead of being unreserved, optimism is a qualified or restricted optimism. What is qualified is not the optimism itself, but the domain over which it extends (Karen Jones, 1996, p. 7).

In Jones's paper, the optimism that might occur in trust is argued to require a optimism on behalf of the trustor that the one that they entrust is committed to what the trustor expects of them, and is competent in the domain of expectation. In the case of the doctor-patient relationship based on the three constructs such optimism ought to be qualified in the domain of the doctor's expertise. Though any doctor (or process of appraising evidence) might be usually reliable, they are fallible, and therefore a

²⁴⁹ By using the word "reserved" I mean the domains of what optimism is held for are narrow and the optimism is held without a firm feeling of commitment.

patient's trust in the doctor ought to be (what I will refer to as) *qualified trust* just as their optimism ought to be qualified in the domain of what they expect from the doctor's care.

I agree with Jones that we qualify the domains of our optimism, and I suggest that it may be worth expanding on Jones's argument that it is not only the domain but also the degree and character of optimism, that at times are rightfully qualified. For example, I may be "cautiously optimistic" that the surgeon who I trust to remove my prostate cancer will do so with clear margins²⁵⁰ and with similar or less side effects as compared to other surgeons. My optimism that my surgeon is competent and reliable etc. may be based on evidence that I am aware is incomplete or fallible. I accept surgery with this urologist as I must choose someone to remove my prostate, so I sign the consent form with "reigned in" optimism that is quite reserved. Though I accept that optimism may be found in many examples of trust, its scope (as Jones argues) and intensity may be on a spectrum, as may trust itself.

If at times "optimism" may seem too unreserved an attitude to hold in whom or what we trust, perhaps the words "plausible expectation", may be more applicable to many forms of trust. The words "plausible expectation" in what we trust may have more specific scope than a generalised optimism, based on what may be reasonably expected to eventuate. Whereas optimism may have a meaning to some readers of possibly leading to a less cautious, less considered type of attitude. Though many forms of trust seem to have constituent ingredients of optimism or plausible expectations, some forms of trust seem to require neither optimism, nor positive expectation about what more obviously seems is to be expected, as discussed in the

²⁵⁰ That is; excise all the cancer and not leave margins of cancer tissue behind.

next ‘therapeutic trust section’ and Holton’s shop keeper example.

It may be seen from this discussion of trust that it may be difficult to characterise trust precisely in all circumstances, and that trust might not be one thing in all situations. Trust can therefore be plausibly characterised as having a spectrum character in the way that it is held and how it is formed. A person can have a more or less emotional commitment to what they trust in. For example, a person may feel emotionally committed to trusting a friend and feel strong emotion if they feel that their trust is not respected and that their expectation of what is trusted is not fulfilled by that friend. Or a person might have less emotional commitment to what or who they trust, for example as might occur when a person’s trusted barista serves them a coffee that is tepid. That is trust that is grounded on more cognitive ways of choosing what or who to trust, where for example a lot of thought, research, verification of credibility of sources, and co-deliberation with others has occurred. This may be compared to a more affective grounding, for example deciding to trust in an instant without much thought as one has a strong, perhaps intuitive feeling that one “likes” some- one and so ascribes to them the possibly ill-founded appraisal that they are trustworthy²⁵¹.

For someone who attempts to adopt a strong position that optimism is always necessary condition for trust, the next section on therapeutic trust may be problematic for their argument that trust always entails optimism of expectation of the trustor towards the entrusted person honouring what they are entrusted to do. A possible counter argument to the notion that optimism is necessary for trust to prevail, may be

²⁵¹ Empirical research from social scientists suggests that we often base our initial judgment of who we trust on subjective and very rapid assessments of their faces. These studies suggest that a part of the brain called the amygdala (that is said to be involved with emotion) is activated when we judge peoples’ faces for trustworthiness. If this research is credible, we may infer from this that often not much deliberation might initially be involved in detecting whom we might trust to cooperate with us (Todorov, Pakrashi, & Oosterhof, 2009).

made that what is called “therapeutic trust” is a special case of trust. However, the existence of special cases lends weight to arguments that trust may have differing meanings in differing contexts.

5.6 Therapeutic trust and normative trust

Authors have built upon Jones’ earlier work on optimism and trust by referring to an earlier 1960 paper pertaining to “therapeutic trust”. An account of this form of trust is given by Horsburgh as,

..therapeutic trust is trust which aims at increasing the trustworthiness in whom it is reposed. It frequently succeeds in this object partly because it tends to establish personal relationship of a certain kind and partly because it tends to render inoperative certain motives for dishonourable conduct (Horsburgh, 1960, p. 348).

“Therapeutic trust” refers to a special kind of trust that conceptually may initially lack optimism that the entrusted will do what is expected of them. Jones also considered that optimism in the domain of what is trusted might be qualified in conditions where one approaches a fallibilist attitude to the reliability of another person. According to Jones,

Sometimes we set about cultivating trust because we think that by trusting, and displaying our trust, we will be able to elicit trustworthy behaviour from the other. When we do this our hope is that by trusting we will be able to bring about the very conditions that would justify our trust. (Karen Jones, 1996, p. 22)

Jones suggests the trustor hopes that the trusted person will recognise that they are being trusted and that such trust will give reasons for the trusted person to do what the trustor expects of them. This is interesting as it might appear from this example

that at times a trustor can trust without relying upon some- one- in this way possibly trust is unlinked from reliability. However, what is relied upon might be not the stated aim of what a person is entrusted to do, but a belief that the trustor can rely upon the recognition by the entrusted person that the trustor is in some way optimistic about that entrusted person's character. McGeer (McGeer, 2008, p. 241) cites the example of parents entrusting their teenager with the house, without good reason to trust them but entrusting them in the hope that the teenager grows into the role of being more trustworthy. The parents may not believe the teenager is yet trustworthy, but feel that as parents, they ought to give their offspring a "chance" and practice in being trustworthy. It seems that the parents believe that trustworthiness can in some way be practiced and be taught through success and failure in being entrusted.

Though the parents may not have reasons to be optimistic in their predictions that their teenager will yet share their commitment to valuing their house nor that he/she is competent to do so, the parents may have faith in the teenager that in the future, the teenager will be more trustworthy. The parents hope that if the teenager is given a "taste of responsibility" and the feeling of what it is like to be trusted, they will grow to be more trustworthy. The parents may not be optimistic in trusting that their child is reliable (in looking after the house) at present but may be optimistic in their hope for the child's future ability to learn to be trustworthy. Alternately, the parents are optimistic not about their child's reliability in one domain, but about showing him/her trust as they believe in a normative value that parents ought to trust their adult children.

Therapeutic trust thus forms a basis for a counter argument to Jones's initial characterisation of trust being necessarily born of optimism that what a "trustor" relies on will bear them good will. In the teenager case, though the parents do not believe

they can rely on their child (according to the counter argument) they additionally do not actually trust their child now, but they have hope that their child we learn to be reliable. The focus of trust in therapeutic trust is not only towards the child now or a particular task but looks beyond them to what we hope they will become. The therapeutic nature of trust is hope that the child will become trustworthy rather than a specific hope that the house will be pristine after the party. Counter argument may be made that, “Jones’ attempt to analogize trusting to hoping leads her account to treat people as trusting others when there is clearly no trust.” (Cogley, 2012, p. 30)

However Jones has not conflated trust with hope as Jones speaks of an optimism of the entrusted one’s good will towards the one who is entrusted, and Jones holds that optimism is not the same as hope. Horsburgh provides examples (in therapeutic trust) where trust occurs without reliance on the person who is trusted and direct optimism that probabilistic appraisals will ground that “therapeutically entrusted” will for example keep a house clean. Trust has in its nature a relational, “duty-setting” aspect that I will now suggest is worthy of adding to our discussion of what trust, particularly as I will apply it to the ID.D.P.R . and the process of E.B.M. A functionalist element to an account of trust is required, that is not just an effect of trust but a component of an account of trust.

Walker’s discussion of the normative character of trust may in part explain the special case of therapeutic trust, in that though the child is not deemed trustworthy to look after the house, it is hoped that the child will learn a duty of responsibility to the family and will safeguard as precious what others value. Such a caring role places the entrusted one in a position of responsibility for what they are entrusted with as the

trustor is vulnerable to the trusted.²⁵² "Trust links reliance with responsibility." (Walker, 2006, p. 80).

Even in the case of therapeutic trust where the teenager is not deemed to be reliable nor responsible with respect to the domain of keeping the house clean, the parents signal trust to their teenager, if not with the firm expectation, at least with the intention of their signalling trust imbuing a sense of responsibility in their teenager. I understand that Walker's discussion of the nature of trust is that it is not merely a matter of predictions of another's good will towards one, but it also involves expectations that the entrusted will respect normative rules about how they ought to behave and relate to me, in ways that these rules, they should. Though trust and reliance are not the same, Walker suggests that trust may be linked to trust in that when we trust we often signal,

..reliance on others whom we expect to behave as relied uponand to behave that way in the awarenessthat they are liable to be held responsible for failing to do so or to make reasonable efforts to do so (Walker, 2006, p. 80).

Such an addition to the nature of trust does not suggest that breaking trust is good or bad²⁵³ but that this is how trusting relationships function. Walker's normative notion of trust may make more sense of the differentiation between reliance and trust, (than may definitions of trust so far discussed) in that when something we relied upon fails, we may not feel betrayal as the thing we relied upon has no duty to us as it is not part of our community.

²⁵² Famously, Hume wrote about the concept that "can" does not imply "ought", however if someone is trusted, both conditions need apply.

²⁵³ Though Walker's discussion on the nature of trust suggests that trustworthiness brings with it accountability.

The entrusted may agree to be entrusted, not due to any sense of good will that they might or might not have towards trustor, but because they value the importance of upholding a duty to be trustworthy to maintain their honour and status as a virtuous person in a community. A trusted person might faithfully uphold their duty of trust for reasons of their honour, but they may also do so because they value the societal role of trust ²⁵⁴ and they believe that the reason to live in a society where the trusted abide by their duty to be trustworthy is for their own, and everyone else's, protection, best interests and virtue. Such an account of trust seems to be a natural fit for the doctor-patient relationship I am arguing for, as by appreciating trust in the manner described by Walker, a doctor and patient may recognise that fulfilling their obligations of trust in one another includes subscribing to norms of expectations that they have agreed to by coming together. At least one norm might be that they can trust that they have a minimum respect for one another and will attend to each other's opinions in the manner of the I.D.D.P.R.

5.7 Trust, duty and care

Being trustworthy demands of the entrusted a duty to *care* for what they are entrusted with. In the case of therapeutic trust, the trustor hopes that the entrusted will in time care for what they are entrusted with or will realise the duty that they have been entrusted with. In the case of the drama class where a student trusts but does not yet believe their classmate will catch them, the student may trust their classmate as they feel that they have a duty to trust the class, or that the classmate has a duty to catch them if they are entrusted to be the catcher. Possible claims that trust is all about prediction²⁵⁵ that suggest a highly rational account of trust may fail to allow for the

²⁵⁴ Also discussed in section 5.12

²⁵⁵ Discussed at the start of this chapter on the nature of trust in health care.

attitudinal character of trust that Karen Jones argues for. I support accounts of trust that include in their definitions if not good will, at least “fellow feeling” or a relational character, as part of what defines many forms of trust. If we give credence to the notion that trust, in part, is an attitudinal emotion, a trusted person (conceptually and morally) ought to realise that a trustor often not just merely relies on them, but that the trustor has formed an attitude towards the trusted, that they are trustworthy.

An objection to this account of trust involving a form of “fellow feeling” may be made that in trusting that a stranger in the street will not gratuitously harm us, it may seem implausible on initial appraisal, to suggest that we have fellow feeling for a complete stranger. However, though we may not have ever met her, we may at least have some minimal relationship with her in her being a sentient, feeling person as we are, in a way a machine is not. We do not “know her” but we may nevertheless trust in certain expectations of her, such as that she, like us, can feel pain, shame etc. and we justifiably may expect that she will behave in certain ways based on such “fellow feelings”. Our trust that she shares fellow feelings with us, may the basis of a level of respect that we have for her and that we trust, she feels for us.

A trusted person may not directly be aware of the trust placed in them by an individual but they may be aware that their *role* is trusted by a community of people which they have not met. By accepting the role in a community of trustors, the trusted may be thought of as having a duty to be aware that they are trusted in a way that may have more value to people than merely being relied upon to perform that duty. A politician might let me down when the politician votes in a way that I did not expect of them, but the politician betrays my trust and evokes a more emotional response in me,²⁵⁶ when

²⁵⁶ That is, if I am not disenfranchised with politics due to certain politicians’ recurrent lapses of ethical behaviour.

they act immorally or in self-interest when they claim to represent their constituents. The politician may never have met me, but they might be aware of the gravity of breaking an unseen constituents trust, as they are being derelict in their duty *of caring* for their constituent's interests over their personal gain.

The example of a stranger above, may be used to suggest an argument that part of trust is a form of duty setting towards other sentient respected beings, to not betray them by breaking certain "co-deliberated upon" normative rules regarding how we are expected to behave towards one another. At least in many communities, we that trust any person who we encounter is duty bound to have at least a level of respect for us and to take care at least not to harm us. In the example of a teenager in the case of therapeutic trust discussed in section 5.6, the teenager is expected to learn certain duties, such as responsibility to respect the family and the parents feel duty bound to have "therapeutic trust" in their child as they have a duty to teach their child to be trustworthy.

In therapeutic trust, trust is in part attitudinal and in part based on reasons and predictions that expected outcomes might occur, with the trustors making predictions as to how the entrusted ought to behave. Not only the trustor as an individual but the broader community may have expectations of how an entrusted person ought to behave. By this account of trust, the "duty setting" relational nature of trust is not just an effect of trust, but is a part of what trust is. (In a similar way as a spade is in part defined by its function) The duty setting nature of trust may be three way; in that (1) the trustor expects that the entrusted has, (or is hoped will develop) a duty to care for what they are entrusted with, (2) the community may expect the entrusted has a duty to act as a trustworthy person ought to and (3) the trustor seems duty bound to actually

have some degree of trust in those they have set up to act in their interest. That is, the trustor should not be ingenuine in their trust as to do so might be manipulative to others who feel a duty to honour what they perceive is the trustors respect for them as signalled by trust. To explain the third point further, it may be construed as wrong if the trustor seems to entrust for example their doctor, when the trustor does not actually trust the doctor and is manipulating the doctor who feels that they have been entrusted. For example, a doctor might feel that the patient trusts them as an expert in addiction medicine who will assist the patient (in what the doctor believes that the patient hopes for) to stop all illicit substances. What the ingenuine trustor (in this case a patient who is on selling prescription medication) is doing is wrongly signalling to the doctor trust with the intention of such signalling influencing the doctor's attitude towards the patient. Such ingenuine trust is used by the patient to manipulate another person to adopt a particular attitude to them and to adopt a professional relationship with the patient whereby that person, a doctor, feels obliged to fulfil certain professional duties to the patient.

A further example of a person feigning trust with the intention of manipulating others can also be seen in counter espionage stories. Double agents may pretend to trust an enemy agent by feigning trust in a personal relationship, when in fact what seems trust, is faked and being used by the double agent to inveigle themselves into an enemy group. Paradoxically, virtuous duty-bound trustworthy people may be manipulated by those who claim to trust them but do not actually trust them. A trustor may for a time genuinely trust another person or institution, and may gain assistance through that trust, then in time change their mind about what they trust. Rather than lose support, a trustor may seek to maintain existing relationships by feigning trust. It may be difficult for others to detect that this trust is fake, as it may seem to be well

grounded and to be the genuine emotional response of the trustor. However, the manipulator's trust is not genuine as the "trustor" does not really have an attitude of trust. Feeling trusted may lead to self-sacrifice on behalf of the entrusted as they may feel a duty to live up to the expectations of the fake, or ingenuine trustor. Lastly by displaying fake trust and manipulating health practitioners to fulfil certain duties (that practitioners feel that they ought to honour to be trustworthy professionals), the fake trustor ignores the virtue of the ones who are trusted.²⁵⁷ That is, fake trust not only is potentially deceptive, but might even seem contemptuous to another person who is trying to be honourable in assisting the ingenuine trustor. Such an argument that draws associations between the effects of trust, distrust and respect, is also seen in more recent work of Karen Jones, where she argued for the "moral costs" of "distrusting the trustworthy". To quote from Jones,

Though the costs of trusting [the] untrustworthy are more obvious they need not be greater than the costs of distrusting the trustworthy. [This may be in part due to] opportunity costs and the harms to others of disrespect and demoralising from being singled out for pre-emptive distrust ²⁵⁸

At least showing distrust where trust is warranted may be honest to the one who feels compelled to perform certain duties, as compared to fake trust. However, in both cases of "distrusting the trustworthy" and "fake trust", disrespect is exhibited to others to whom respect (and genuine trust) ought to be shown. In addition, harm can occur

²⁵⁷ This discussion's relevance will be returned to in the development of the implications of trust, with relation to a doctor's duty to care as the doctor has been trusted. The doctor, as a trusted professional, has a duty that supersedes merely being a predictive tool as the doctor is expected to uphold certain virtues such as being caring, compassionate and beneficent. Fake trust is unjust as it defiles the virtue of the carer who fulfils the expectations of trust and fake trust is disrespectful to the carer in the way it uses the care as a means to a patient's deceptive ends.

²⁵⁸ From an unpublished seminar work sheet titled "Distrusting the Untrustworthy" that was presented at a Monash University Philosophy and Bioethics Friday seminar on 25.10.2018.

to others who might require a doctor as the trustworthy doctor might find that their reasons to be diligent in fulfilling duties to the future patients are less warranted if they have had a number of experiences of being manipulated by patients by being beguiled into believing that they were trusted. Such an example might be a case of the “demoralising” cost that Jones mentioned in the manner in which ill-founded distrust might affect a doctor. The “opportunity cost” in this example might be the lost opportunities for the patient who distrusts a doctor who is actually trustworthy, with the implications that such distrust might have for the patient and those who rely upon the patient remaining in good health. Wrongful distrust might work in the opposite direction in the doctor-patient relationship. A doctor might distrust a patient who ought to be trusted by wrongfully assuming that a patient with from a particular demographic or with certain appearances is “drug seeking” from the doctor. The doctor does not trust that the patient respects their professional opinion or wants their care. Not only is there an opportunity cost to the patient in such a circumstance where the patient might be refused care by the doctor, but the doctor might seem to be disrespectful to that patient (in the way that people appraise others to be of a different “moral tribe”) by giving the impression to the patient that the doctor believes that the patient is not worthy of a caring professional relationship with that doctor. The doctor seems to be neglecting their duty to care for the patient as they wrongfully distrust the patient or the patient’s motives for coming to see the doctor.

I have presented these examples after discussing “fake trust” and possible consequences of distrusting the trustworthy to support a claim that particularly in health care, patients and practitioners ought to be reflective and careful not only about what and who they trust but also what/who they distrust. Failure be open to appraising what they trust or being careful to consider what factors might influence how they come

to trust might bring them opportunity costs and adversely affect their duties and relationships with others. Plausibly a doctor or patient can trust or distrust each other, or a health belief, for reasons that others believe are unwarranted to the other person. By adopting a fallibilist attitude that can facilitate us to be open to changing what we determine is trustworthy or untrustworthy, we may be more open to respecting the opinion of others who seek to show us influences on what we trust/distrust that we might not have considered in differing ways. Being open to co-deliberation with others about what influences what we deem trustworthy might not increase the plausibility of what we trust, but such an openness can show others that we respect them enough to at least consider their opinion.

5.8 Trust and bias in health care decision making.

Unconscious bias has the potential to influence how a patient or doctor comes to trust a health belief or practitioner in a manner that might be imprudent for the patient, insofar as that bias might lead a person to not attach value or give credence to evidence that they may have wished they had been aware. A more conscious form of bias might have similar effects but furthermore be a form of prejudice that has the potential, like implicit bias, to not only be imprudent for the patient but also lead them to show disrespect to others. For these reasons, patients and doctors ought to be cautious in how they trust the processes that lead to beliefs or practitioners in health care and be open to appraising what they or others highlight to the patient might be a bias that they hold.

I am not here claiming that a trustor always having a bias may be a legitimate part of a definition of trust. However, an understanding of “bias” may be useful in understanding how to distinguish between degrees of trust. Trust might be held by a

person not only based on their prediction of how they “assign the ...values of the probability of certain probabilities” (Gambetta, 1988, p. 217), but differing types of trust may also be held by a person based on varying types of bias that this person holds. A person might be more or less aware of their biases. The reason I seek to highlight the importance of such a difference in the context of the doctor-patient relationship is that in cases where in my role as a doctor a patient has treated to me as a “moral other”(Greene, 2013), I have wondered whether this might be due to the patient’s implicit or conscious biases involved in what seem to be ill-founded beliefs that they see no reason to reappraise in light of evidence I may encourage them to consider.

I claim that patients and practitioners ought not to bypass their usual defences against some forms of harmful bias, as without due deliberation or some reflection, unqualified trust may become more a form of unreserved faith that has potential to render a patient particularly vulnerable to being guided by harmful beliefs or emotions. This potential vulnerability might not only be imprudent for the patient, but it can also lead the patient to disrespect to others.

Kahneman and others discussed implicit “cognitive biases” as being a result of heuristics (fast intellectual shortcuts) to make assessments of subjective probability. Kahneman’s book argues that the use of heuristics may lead to “severe and systematic errors” and are used to “make subjective assessments of probability...based on data of limited validity”. (Kahneman, 1982, p. 3). Cognitive bias is when an agent adopts a belief or makes an inference where evidence is limited or not available or “judgements ...often departed from normative standards based on probability theory or simple logic” (Haselton, Nettle, & Andrews, 2015, p. 727).

Though the work on bias is extensive, I seek to discuss a broader meaning of bias that is not just cognitive but emotional. Dictionaries include definitions of bias as; “an inclination of temperament or outlook especially a personal and sometimes unreasoned judgment”²⁵⁹. Or from Collins “Bias is a tendency to prefer one person or thing to another, and to favour that person or thing.” Or “Bias is a concern with or interest in one thing more than others” or another meaning may be “that to bias someone means to influence them in favour of a particular choice”²⁶⁰. Bias appears to have differing meaning in different contexts and often is used with negative connotations. Some bias may be explicit bias that an agent is conscious of. My understanding of bias as relevant to health care is that bias is on a spectrum of being more or less implicit *or* conscious; a more automated type of belief or attitude that is generally less based on reasonable deliberation and has some salience setting effect for the agent. Bias may be considered (by self or others) as more or less well-founded and justified, and like any attitude, bias may be more or less firmly held or informed.²⁶¹

Bias has similarities to trust in that bias might have motivating effects in the ways in which we form beliefs. However, it is difficult to determine the extent to which any given agent’s judgements and decisions are influenced by bias/es. An agent can be more or less aware of their biases or of the underlying reasons that they place their trust in

²⁵⁹ <https://www.merriam-webster.com/dictionary/bias>

²⁶⁰ <https://www.collinsdictionary.com/dictionary/english/bias>

²⁶¹ Furthermore, the attitudinal element of bias, may have a phenomenological component to it that legitimately may vary at differing times for each person. Importantly and beyond the scope of this thesis, just as with Gettier cases, chapter 2, bias may be more or less justified or true and it requires further research to establish how we may determine who is biased and how much such bias influences them. For example, we may think a U.S. refugee who fled a gulag from Stalin’s totalitarian state, seemed justified in thinking the FBI was observing her in the McCarthy era. As an atomic physicist she may have good reason to assume she was under surveillance and having seen how humans can behave in Stalin’s regime, we may judge her bias to not trust police and government intervention as justified, based on her experiences. Others may view her biased attitude “to be a bit paranoid” as being understandable compared to those who grew up in the U.S. She may be more or less aware of her biased attitude and more or less influence by such bias. Similarly, others may be more or less aware of her bias. The beliefs she forms, influenced by her bias and beliefs that inform her bias, may be debated as may her attitude. Further research in this area may argue that co-deliberative processes may evolve that will assist the scientist and her community determine what bias affects her and to what extent her biases are considered justified and true.

one person or another. Though a wise person does not necessarily claim that they make judgements free of bias or without provisionally trusting in something, a wise person arguably attempts to understand what influences their judgements, and attempts to make certain allowance for how bias/es might influence what they trust. By being humble and accepting their fallibility, a wise person may become more astute at detecting when they are entering areas that they are unwise in, or need to be more wary of bias in. In the schema of the three constructs, doctors who read journals can be made more aware of their common biases (I. Scott et al., 2017) which might influence their efforts to advance ethical, effective care. I do not claim that doctors do always reflect on their biases, but that the processes of E.B.M. facilitate such reflection, by encouraging people to appraise the opinions of others, to attempt to be aware of confounders and adopt a fallibilist attitude to their beliefs. Rather than define bias as a mysterious propulsive force that moulds our attitudes, bias, like trust may be helpfully regarded as being more like a filter,²⁶² that alters how further evidence is interpreted. To quote Jones, “Affective attitudes are biasing devices. They have the following roles: They (1) focus attention, (2) direct enquiry, (3) shape interpretation, (4) structure inference, and (5) rearrange action options in a hierarchy of salience” (Karen Jones, 2019, p. 958) If indeed some types of trust have these effects, increased awareness of possible filtering effects of what we trust or are biased by, may motivate a wise person to better understand how biases affect how they think.

Alternative definitions of bias may be formulated that highlight individual elements of the above conception of bias. An argument might be made that bias is never conscious, but is only implicit and to an extent, something beyond an agent’s control.

²⁶² See Jones quote on the nature of trust in the introduction of this thesis.

Implicit bias might be seen on first inspection as something negative; an impediment to the rationality that may “save” one from acting out of bias, without due deliberation. Implicit bias may be problematic as it may lead a person to hold attitudes that conflict with what they think and say are their core beliefs.²⁶³ In this way implicit bias may erode the agent’s sense of self if internal logic is important to them. In common language use, we may hear disparaging comments that scientific papers have publication bias, or that a job selection panel is biased towards hiring men. By this view of bias, if bias is not an automated way of thinking, then it is not really a bias but a preference a person can choose to hold or not. However, there may be spectrum along which a bias is more or less implicit and at what stage a conscious preference becomes an unconscious bias.

A further notion of bias describes bias as dominantly attitudinal, based on unbalanced or tenuous evidence. Bias attitudes may be thought of as automated ways of making “associations” that are a form of “alief”, that is an, “innate or habitual propensity to respond to an apparent stimulus in a particular way. It is to be in a mental state that is... associative, automatic and arational.....Typically, they are also affect-laden and action-generating” (Gendler, 2008, p. 641). For example, from years of growing up with narratives and movies depicting certain ethnic groups as “bad” and never meeting people of that ethnic group, an inexperienced adult may form associations and schemata of how people of one ethnic type think or behave. Bias and prejudice may evolve towards that “moral tribe” (Greene, 2013).

²⁶³ Bias can be plausibly held at times, especially if it is implicit bias, influence a person to prejudice or prejudgement on a matter.

However, attitudes, like preferences, may be open to deliberation and change.²⁶⁴ I suggest that bias may be viewed as not necessarily always leading to irrationality that we might often be vulnerable to, but as a type of attitudinal belief that we (debatably) may not have thought through as much as other beliefs. Alternatively, we may have come to accept a bias after deliberation and appraisal of past evidence and so use the bias in the manner of a heuristic. Gigerenzer (Gigerenzer, 2014) has argued that the use of heuristics do not necessarily lead to poor decisions and, to the contrary, that the use of heuristics may lead to better decisions with or without paucity of evidence. It is plausible to hold that, with better training in basic logic and principles of probability, people can become more effective in using critical reflection to appraise their biases and to determine what biases may more reasonably influence what they trust. We may choose to appraise a bias (if aware of it) that we have previously accepted, as new evidence arises, and we see reason to change.

Biases may therefore be both helpful²⁶⁵ and harmful in differing contexts and an agent may have more or less power to resist bias and consider salient evidence to revise their attitude and beliefs. I am arguing that as part of assisting patients to gain substantial understanding, ethical care requires carers to inform patients when the carer is influenced by bias, or trusts to the level of having faith, in things or people that may not be what patients would reasonably expect of a practitioner. With years of clinical practice, a practitioner may have learned from mistakes that they have made and mistakes that they have seen in others. By attending to bias and acknowledging

²⁶⁴ The U.K government has a unit called "Prevent", set up to counter radicalisation of individuals, premised on the notion that a person may change their extreme racist biases. Indeed, nudging may be construed as a form of libertarian paternalism that attempts to sway people's biases.

²⁶⁵ For example, as a G.P. I may be biased against trusting the *motives* of a new patient's request for "Valium" who has drug addiction issues as in the past people have asked me to prescribe them Valium they intend to misuse. My bias is supported by regulatory bodies advising exercising great caution in the prescription of drugs with a propensity to addiction, particular to people who are already addicted to other substances. My bias is also well-founded as I have clinical experience that points to the lethal consequence of Valium misused with other drugs.

their own fallibility (and that of others and the processes they all refer to) wise ethical carers can become more expert in what biases are more salient in health care. Carers may not only be expert in care, pathology, treatment, and prevention but can become expert at advising a patient on biases which are especially prevalent in the area of healthcare decision making. As doctors have a role in promoting substantial understanding for informed consent, so too doctors have a professional role to become expert in bias as occurs in health care and highlight to patients the doctors' and patients' biases as relevant to the clinical context.

Principles of bioethics hold the importance of informed consent and substantial understanding in health care. (Beauchamp T.L, 2001) In special circumstances, where the patient may suffer avertable, plausibly foreseeable serious harm or betrayal if they trust while subject to some types of implicit bias, the health carer ought to be able to ask a patient to consider appraising that patient's bias that is leading to a foreseeably dangerous health choice, or bias that impairs a patient's ability to maintain dialogue and respect for those who care for the patient. As a doctor has a duty to advise a patient of the known common or salient harms of a drug, so too a doctor ought to where possible be able to advise a patient of commonly known biases that have influenced people to make decisions that have caused patient harms in the past.

In chapter one I argued that ethical care embraces fallibilism. I argued that ethical health care requires carers to encourage (themselves and) patients to give only provisional trust to their intuitions and values, and not to dismiss outright the possible veracity of trust in external evidence such as that derived from processes of E.B.M.; even if evidence from science conflicts with what patients have trusted. Here I am arguing for the further claim that ethical doctors are morally obliged to foster such

provisional trust and to not encourage care that is based on unexamined biases of a doctor or patient where others who seek to support patient care suggest them that they have such biases and that their biases are misleading or may lead them to harm others.

In adopting a fallibilist attitude, those who are guided by processes of E.B.M. are assisted in being made more aware of bias in healthcare. For some years peer reviewed E.B.M. journals have required authors to list their “declaration of interest”. Though a doctor may receive various forms of assistance from the pharmaceutical sector to engage in research that they publish, such an interest that they declare to the journal does not necessarily bias the doctor’s opinions to favour or disfavour the subject of research. Though research might lead a reader of a journal to consider that a publication’s authors might have certain biases (Goldacre, 2012), this or consideration by the reader need not be the case. An interest does not necessarily imply a bias; however, a bias might be more possible with an interest. However, authors publish while aware that readers have the opportunity to take possible bias into account when they consider the clinical relevance of the paper in question.

The rationale for such declaration of interest is that some research can potentially promulgate individual doctor personal interest, ahead of more virtuous ideals of advancing patient wellbeing or health care knowledge and that readers ought to be made aware of such possible influences on what is published. Bias may be expected to be declared in journals, however importantly in the doctor-patient relationship, patients and society reasonably expect that a carer ought to declare where personal interest can bias the carer towards certain choices, when these choices are to the detriment of patient centred care. Examples may be of surgeons using prosthesis

manufactured by medical device companies with whom they have financial links, or G.P.s enrolling patients in “clinical trials” for which the G.P. received material gain (Lo, 2009). Where in publishing, journals predominantly stipulate that potential financial bias must be declared in order to publish, in the doctor-patient relationship many other (additional) biases may influence a doctor’s and patient’s beliefs and attitudes (Blumenthal-Barby & Krieger, 2015; I. Scott et al., 2017). Though a G.P. might think that mounting antibiotic resistance is due to other doctors’ inappropriate prescribing, (Hallsworth et al., 2016) that same Australian G.P. may become aware of their bias through reading the “National prescribing service” review sent to them with details of their own prescribing data, or through clinical audits and discussions with colleagues.

Prudentially and out of respect for friends and family, patients ought not to give unqualified trust to the individual doctor for their health care, but should contingently trust that the doctor (tries to) represent the fallibilist system of E.B.M. Though a degree of optimism may be common in how doctors and patients come to trust in health care matters, such trust ought to include a qualified sense of optimism that allows them to be wary of bias, and that influences them to be swayed by the opinion of others to whom they ought not to attend without caution.

5.9 Trust, and partiality in health care decision making.

In the context of the doctor-patient being conducted in the schema represented in diagram 1, both parties ought to be aware of partiality and be qualified in how they come to trust health beliefs that they use in health care decision making. What we deem to be trustworthy may be unreliable due to our error, biases or what we are partial to. The very fact that we trust someone, or something may make us partial to

something or someone, and may render us vulnerable to what or whom may prove untrustworthy. This is not to say that in the doctor-patient relationship that partiality should play no role in how patients and doctors determine what they believe is trustworthy. Rather awareness of such partiality may avail us the opportunity to question what we believe is trustworthy in certain situations. At times, such as in some health care, care requires caution in what we trust or are partial to.

Partiality is important in friendship and close relationships (Hawley, 2014; Wolf, 1992), and partiality and bias might have similar meanings. However partiality suggests an affinity towards something or someone, whereas a person may have a bias that they do not like, e.g. a racial bias, as seen in the implicit association test ²⁶⁶ (Nosek, Hawkins, & Frazier, 2011). Psychological studies of bias suggest that we may be partial to our firmly held beliefs (Kahneman, 1982). We may trust processes or people that support certain beliefs that we are partial to and be less diligent in checking the veracity of the facts behind those beliefs, than when we have less emotional attachment to or are distrusting of processes or person behind a belief. All other things being equal, the bias literature suggests that we are, not compelled to believe in something, but are more likely to believe what we *like* to believe. (Gorman & Gorman, 2016). Being aware of what we are partial can give us the opportunity to discern possible biases that we may actually want to account for in our health care decision making process. Awareness of bias can also lead us to appreciate new data, or to find differing meaning from data which we see but do not appreciate (as per work on “inattentional blindness” (Simons & Chabris, 1999)).²⁶⁷ Increased self-awareness of

²⁶⁶ This test is a large online test run by Harvard that attempts to quantify peoples’ implicit biases. E.g. unexpected racial bias.

²⁶⁷ If we draw from the well-known experiments by these researchers, where a gorilla cannot be seen in front of people appraising a recorded staged basket-ball game for an element of the game, conclusions are

bias has the potential to make us more potent in serving our best interests, rather than simply pursuing what we currently “like”. I am arguing here that it is prudent to be fallibilist and to have a degree of scepticism in what we, and others, trust. Though each patient and doctor must make their own decision, and a fallibilist has a degree of scepticism as to what they trust, it may be prudent to seek a degree of guidance and ideas from others around us who are suitably qualified, to check the background grounds of what we trust. Carers ought to aid patients in checking the credibility of what patient’s trust, just as I will argue that carers ought to promulgate conditions of informed hope for patients.

In health care we may not like something, but we may know we that must go ahead with it for the sake of our long-term interests. We also may go ahead with something in health care that we are not partial to, because we believe that it is important to consider the interests of others who depend upon us to remain in good health by undergoing an unpleasant procedure. We may accept compromises in many areas to achieve what we hope for. Health care that is guided by those who adopt a fallibilist attitude abounds with compromises. We may seek to have expensive painful and rarely harmful vaccines so that we may travel to places where yellow fever is endemic. In the 2020 pandemic, the usual processes of E.B.M. were compromised as the usual peer review process and four phases of clinical trials were modified, with examples of harms and poorly conducted research (Toumi et al., 2020) and benefits in the rapid development of effective vaccines. A naturopath or a devout Roman Catholic may not be partial to their use but choose to use contraceptives and subvert nature (or a Papal encyclical) to avert the pregnancy that their body is primed for, but that they seek to

drawn that what we perceive is gated by what we look for. In this experiment, people do not mention the gorilla they must have seen as they are concentrating on other aspects of what is in the environment in front of them.

prevent. Compromise may be inevitable in health care, and we may compromise values that we are partial to, in favour of values that promote our health. Part of Emanuel and Emanuel's article on the I.D.D.P.R. argues that it is a health carer's role to assist a patient to reflect on their values in the context of health care (Emanuel & Emanuel, 1992). The very partiality that we come to when we trust one thing, may require the guidance of another source that we trust, when bias misguides us in considering another matter. A patient may need to choose between differing values where choice of one value necessitates compromising another value. Principles of co-deliberation and the construal that we are relational beings²⁶⁸, may be used to support arguments that at times we may be open to allowing for qualified influence by those around us who are most qualified in relevant areas that pertain to certain values.

We might trust someone without liking them – for example as we may trust a neurosurgeon – but we expect partiality and liking in friendships. Partiality is also seen in “moral tribes” (Greene, 2013) where those of one's own group are assumed to be friends and to have the “correct” morality. Conversely, members of another tribe are deemed to be “moral-others” and are always “locked-out” as “moral-strangers” whom are not respected and not “liked”. They are “locked out” in the sense that they are not permitted into the domain of consideration and also dialogue with the other. It seems common practice to favour members of our family over strangers, and it would seem odd for a person to not be more affected by the suffering of their child versus one who is remote to them and only seen on television. The partiality of friendship may let us tolerate behaviours that we might not tolerate in others, and to trust that the friend stands up for our interests (e.g., in therapeutic trust). Partiality may lead us to take

²⁶⁸ In the sense that we tend to live in groups with relationships. even if remote, with other persons.

less account of salient facts, or to tolerate epistemic irrationality. (Stroud, 2006). Partiality in the forms of feelings of friendship or “liking” a health practitioner, may bias a patient to trust a health practitioner and to ignore salient evidence that the patient otherwise may have considered material to a decision. It is risky for a patient to base their trust for a health practitioner—principally on liking them, or on a feeling that the practitioner is actually like a friend, as such partiality may lead a patient to discount salient (but what the patient would normally think) unattractive evidence or reasoning. Furthermore, conventional professional ethical boundaries hold that though elements of friendship may exist in the doctor-patient relationship, the relationship’s purpose is contingent on other factors rather than those which are central to friendship. (Oakley & Cocking, 2001) (page 51) (Illingworth, 1988) (Fried, 1976)

Steve Jobs trusted his usual “magical thinking” way of making a decision, in his health care, but possibly with lethal consequences. Jobs might have been partial to “magical thinking” as such thinking had been contributory to his success in business. (Walton.A.G, 2011). A patient may be partial to forming trust in ideas or people in a certain way, and might discount other pertinent beliefs that are relevant to what they decide to trust. Partiality, though necessary for friendship and forming beliefs in a way that has worked for a patient in the past, may sometimes function as a bias that makes a patient more likely to determine on ill-founded grounds that something/someone is trustworthy. What is trusted to eventuate, may occur, but is unlikely to occur. Ill-founded grounds for determining what is trustworthy rest on epistemically flawed grounds that may lead a person to trust, what or who is untrustworthy. Partiality can influence patients and doctors to not seek out further verification that what they trust is actually trustworthy, and to be less reflective, as they have chosen to deny possible

conclusions from certain types of knowledge.²⁶⁹

Though we may trust based on the best information that we have at the time, we may in the future look back and realize that our trust was ill founded, in a somewhat similar way to how hope may prove to be in vain. We may have made epistemic mistakes in forming our beliefs as to who we consider trustworthy, or we may have let our biases make us more partial to an untrustworthy person or system, or we may have been manipulated or deceived in forming trust.

5.10 Faith and Trust lie on a spectrum of belief and emotion and this can have moral consequences in health care.

Having discussed the need for doctors and patients to be self-reflective and responsive to each other's biases and partialities in how they determine what they trust in health care, I now turn to another factor that may influence how doctor and patient might treat each other due to what they trust. Faith which can be understood as a form of trust that is at the end of a scale of trust which precludes a person from appraising the views of the other, can "lock the other out" (see section 5.9) and show them disrespect. In health care patients and practitioners ought to trust individuals, processes or health related beliefs with a qualified type of trust rather than the unreserved trust of faith.

Having discussed what trust may be more generally, in this section I seek to begin illuminating the character of what type of trust may more ethically be involved in health care, by contrasting a cautious, qualified trust that is more responsive to a person's cognitive processes and deliberation with others, with types of trust that are less

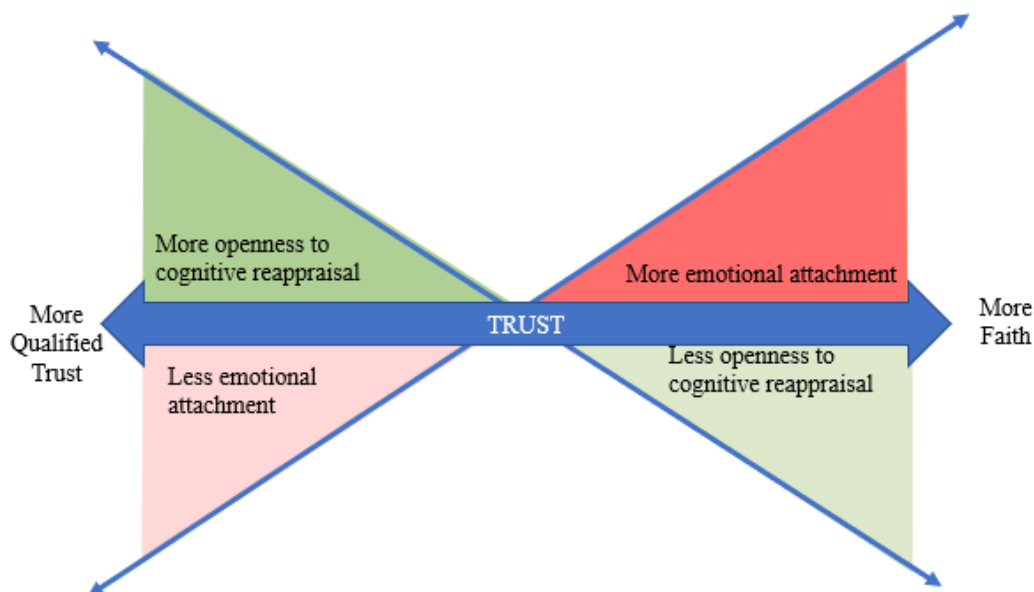
²⁶⁹ See also similarities with hope section re false hope.

reserved or are subject to such appraisal. As I previously explained, there may be two differing ways in which a person comes to trust someone or something; firstly a person may come to trust based upon a greater or lesser amount of cognitive appraisal and deliberation about various sources of evidence that a person appraises, in determining what they believe is trustworthy. Though cognitive consideration by a person alone does not define trust, how a person comes to trust something may nevertheless relate to whether their trust is based on more or less strongly grounded evidence. Furthermore, a person may have trust that is based more upon their affective elements than on cognitive processes in its derivation. That is, a person might decide to trust something with little use of cognitive processes but because they feel that their strong emotions are enough for them to believe that something is trustworthy. For example, a parent may trust that their child will eventually look after the house, without good empirical evidence that this will occur, but because they simply have a “good feeling about their child”. There might be a spectrum character to how trust is formed with differing intersecting axes of degrees of cognition and emotion, involved in how a person comes to have an attitude of trust. Furthermore, as I have argued that trust might be held with a greater emotional commitment to what is trusted in some domains and less commitment to what is trusted in other domains. Somewhere at one end of these intersecting axes of degrees of emotional attachment to what is trusted and how much cognitive or affective input a person uses in coming to trust something resides a level of level of trust that may be felt by a person as faith.

A person might come to faith with little cognitive appraisal as to why they have such faith, but because they simply have such a strong positive or “good feeling” about what they have faith in. For example, parents may feel a strong emotional commitment to a child that they have faith in. The parents may not feel that they need to rigorously

appraise the evidence that supports their faith, or that they need to justify to themselves or others why they have such faith. Alternatively, a person might come to have faith in something or someone with a lot of cognitive effort and varying amounts of emotional attachment to what/who they have faith in. I construe qualified trust to be more at one end of spectrum of emotion, and some forms of firm faith to be more at the other end of a spectrum of the emotion of trust. Following is Diagram 2 that attempts to explain my understanding of the spectrum nature of trust that a doctor and patient ought to be aware of when they make health care decisions.

Diagram 2: Axes of degrees of trust



A discussion of the nature of faith is important in health care as I am arguing that in most ethical health care, doctors and patients ought to have qualified trust in the processes or people that influence them to hold beliefs that they use to make health decisions.

One definition of faith may be that faith is,

a rational attitude towards a potential object of knowledge which arises when we are subjectively certain it is true even though we are unable to gain theoretical or objective certainty.²⁷⁰

This definition posits faith as having reason behind it, not purely fantasy, and understands faith as what lets us accept knowledge without objectively certain evidence. However other definitions of faith, suggest that faith may be a less rational type of attitude. Hart suggests a faith to be a,

...continuum of words connoting belief based on the degree to which they rest on evidence of the senses. Faith requires no evidence; trust is an expectation based on inconclusive evidence, is tolerant of uncertainty or risk; confidence is a strong conviction based on substantial evidence or logical deduction. Trust thus stands in the middle of a continuum of words for belief mixing extremes of blind faith and open eyed confidence..... from Keith Hart in (Gambetta, 1988, p. 186)

While I do not accept without debate that faith requires “no evidence”, as faith surely

²⁷⁰ <https://kantphilosophy.wordpress.com/technical-terms-of-kantian-philosophy/>

has an origin ²⁷¹, Hart illustrates that there may be a spectrum between the degree of cognitive appraisal that goes into forming trust to the degree that is faith. This discussion highlights that trust is a type of expectation or attitude, and what may be debated is how reason must be utilised before trust is termed faith. Faith may be a form of trust, with elements of emotion and reason, as per Jones's above definition of trust, and both faith and trust may be justified or not until more definitive evidence becomes available. Baker claims that trust should be regarded as "a kind of commitment, a state of conviction that is also an inclination of the will" (Baker, 1987, p. 10).

It may be that faith implies a deeper form of commitment to a belief, that the agent has decided to accept and not to deliberate further. Such a position sees faith as an attitude of an agent who abandons the possibility of presently coming to further understandings in a domain at question, so trusting a belief as they consider they have no other means of making a choice. As Baier says of faith, "Faith and hope I take to involve acceptance of belief on grounds other than deductive or inductive evidence of its truth. ...Faith is the evidence of things unseen" (Baier, 1980, p. 133).

Importantly to this thesis, faith is adopted when an agent forsakes their usual processes of reasoning, or when the agent decides that they cannot comprehend certain "unseen forces" without necessarily accepting that their actual emotion of faith is reason enough for them to trust something. Their very powerful feeling of faith is seen as sufficient evidence for them to trust something to the extent that they now believe that they have no need to consider other views that seem to shed doubt on

²⁷¹ The "origin" of faith might not be beliefs derived with support from empirical evidence, but rather faith can be from what a person feels, even if such feelings are derived from false beliefs or due to sensory input even from, for example, hallucinogenic substances.

what they have faith in. By this view of faith, a belief is accepted, “in a leap of faith”, as an agent comes to an understanding that they have now no need to work things out further. Impressed by their feeling of their faith as being sufficient evidence to trust something without any doubt, a person feels that they may abandon the usual evaluative conditions and just reach a decision of what to trust, in faith. What may be open to debate in this account of faith is whether in each situation, it is premature to accept that further evidence is un-attainable or not comprehensible. For example, a patient may feel that they will simply trust the surgeon and go ahead with major surgery as they cannot decide for themselves whether to have the surgery or not since they feel that they cannot understand medical matters. They decide that they will simply trust that the surgeon will tell them what is best for them as they like the surgeon and have every faith in the surgeon. However, the surgeon may advise the patient that she feels uncomfortable with such responsibility and that in fact if the patient will attend to the surgeon, then she is likely to be able to explain the relevant medical matters and that the patient will be able to substantially understand the surgery and decide for himself what is best for them.

A patient may claim that they have “faith” in their cardiologist to recommend the best therapy for heart failure and that the patient need not be diligent in understanding their treatment options. However, faith alone is not necessary here, as a patient can conceivably with time and diligence come to understand heart failure and its therapies to the level that they have no need to have faith in the doctor, but can have a more qualified, type of trust. Such trust is grounded on mutual respect and the patient acquiring substantial understanding about their therapy, as the basis of the relationship.

To have unreserved faith in a health idea involves having a bias or partiality, to that idea with a commitment to that idea to the extent which involves a lack of proportion between the external available evidence and the depth of belief. In this section I contrast qualified trust, with a less deliberative form of trust that I suggest is more like unreserved faith, in that though faith may be based on reasons (e.g. that the feeling of faith is strong), strong faith may lead to dogmatically held beliefs in health care. Such dogma in health care, is antithetical to my arguments in the previous chapter that defends fallibilism in health care.

I may claim to have “faith” in my surgeon and their ability to remove my prostate. It would seem inappropriate in this context for faith to be unreserved and unquestioning. It is outside professional norms (of our society) for a doctor to care for a patient who has unquestioning trust in their surgeon to the degree of having unreserved faith in the surgeon.²⁷² In patient centred health care such as ought to occur in the schema of the three constructs, the doctor may in some ways be akin to (but not the same as) a friend, teacher and mentor. Ideally the doctor-patient interaction is one of mutual respect and is a two-way interaction with agreement reached after mutual consensus. In the I.D.D.P.R, the doctor is not one who tells the patient what treatment is best for them and the patient consents as the patient has “utmost faith in the doctor” and will “do as doctor says” without questioning doctor’s authority. In the model of ethical care,

²⁷² If we think of cases of patients with cancer seeking cure from “Dr.” Milan Brych (whom former premier of Queensland Sir Joh Bjelke Pederson supported) we may postulate that for patients who consulted Brych, faith in Brych was dominant over a more qualified form of trust in coming to seek his alternative medicine cures as there was little or no evidence that Brych was competent, beneficent or qualified. Faith healing may also be seen in cultures where faith in mysterious powerful forces is a more dominant way of forming health beliefs. Further examples of faith in health care are seen at faith healing services in some churches where people are “healed” by prayer (Chapter 4). In the traditional practice of some first nations peoples, “pointing the bone” may have powerful effects that may be attributed to expectation and powerful nocebo effects; however such effects may also be seen as due to a belief in the presence of powerful forces that may not be understood by the subject of the bone pointing, who feels little power to resist such forces.

the patient may plausibly trust the doctor or have probationary “faith” in the surgeon’s abilities, but such faith is limited and really is more on the spectrum toward qualified trust than the unreserved trust of extreme faith.

More qualified forms of trust are based on reasons that may be debated, than may occur in the extreme version of trust seen in dogmatically held faith. Qualified trust may be more readily revised as the convictions of trust that rest on revisable reasons, are less firmly held attitudes, than the firmly held trust that is dogmatic faith. The possibility of revision of beliefs is not only humble but allows for co-deliberation with others and respects that others may have a view that is well-founded and ought to be considered. Whereas if health beliefs are trusted in a manner of dogmatic faith in the matter at hand, co-deliberation may be impossible.

Furthermore, in health care if dogmatic faith is adopted, disrespect might be shown to others who have differing views. Firm faith negates the possibility for a patient to consider further evidence from others who seek to have a dialogue, as dogmatic faith accepts no further evidence, revision or the possibility that the views of others can be valid. Disrespect is shown to a practitioner by shunning those deemed by the patient to be “not of the right faith” thereby “locking out” the practitioner out from meaningful dialogue or even basic consideration by the patient.²⁷³ I am not here claiming that a patient always ought to engage in co-deliberation with the practitioner in all circumstances. However, “locking out” the practitioner may give the practitioner the impression that the patient thinks the practitioner’s views do not matter. In addition, if the faith can lead to un-warranted distrust of one who thought they were trusted, faith-based health care decisions may also lead to disrespect of a doctor who feels a duty

²⁷³ As may occur in “moral tribes” as discussed above.

to care for a patient in attempting to discuss perceived biases or alternative well-founded beliefs.

5.11 Moral implications of trust in health care

In health care harm may come from more firmly held forms of trust that lie on the spectrum of being firm faith, as contrasted with more qualified forms of trust. Faith may allow an agent to hold beliefs as “subjectively certain” while the agent rejects theories or beliefs widely accepted by others; so faith may stifle further co-deliberation. In health care, firmly held faith can render debate impossible should a patient who is embarking on a futile health choice, encounter carers who care for the patient and fear he/she is on a lethal trajectory. Whereas if the patient’s health choice is based on more qualified trust, with less strong an emotional commitment to a choice, a more fallibilist position seems enabled by the patient and there is room for respectful co-deliberation. Such care might now be a rare occurrence in the standard Australian G.P. context, but as I have discussed, in the past patients had and were expected to have great faith in their doctor. The process of E.B.M. was in part developed to facilitate patient centred care, whereby the patient is encouraged to take part in medical decision making and to not simply have faith in their doctor. In some current settings such as in a Pentecostal healing service or perhaps on so-called “non- western cultures”, faith is firmly held as being sufficient evidence for a patient to participate in what is said to be a health practice. A degree of “good” faith may be important in the therapeutic relationship and may aid the beneficial effects of placebo, however faith might lead a patient to defer effective care if they accept a belief in a dogmatic fashion. A patient might state that they will deliberate no further and argue that this lack of further deliberation is justified “as they have firmly held faith” that a health outcome will occur,

or that their faith in the carer is immutable.

Importantly, in setting of the I.D.D.D.P.R the patient or doctor's faith in a belief that they trust without reservation has the potential to "lock out" the other from dialogue on a point of difference of opinion in a way that a more a qualified form of trust allows a person to adopt a more fallibilist attitude and be open to re- appraising what they have trust in. A patient's immutable faith might give them a sense of self power and belonging to group who holds a particular faith, however dogmatic, unreservedly held that will bar a person from "seeing" other beliefs, could render the patient vulnerable if this sense of power is illusory or they are deceived by their faith.

5.12 Trust, power and vulnerability

In this section I will argue that our need to trust other people on a societal and personal level, can make us vulnerable to being harmed or exploited (Baier, 1986, p. 242) and that uncontroversially ethical health practitioners ought to protect those vulnerable, whose care they are responsible for, as protection from harm, is part of a duty of care.²⁷⁴ In health care a trustor ought to rely upon reasons as well as emotions to reasonably (in the sense that they can discuss justificatory reasons with others) believe that what or whom they trust in, will plausibly meet their expectations. We need both sources of guidance as both reasons and emotions are vulnerable to bias (Bortolotti, 2014) and to attempts by others to exert power over the individual who trusts Trust and vulnerability are associated and it is important for practitioners and patients to be aware of this association and the nature of their trust.

²⁷⁴ The duty (ie something one must or is required to do) to *care*; may have a legal sense "the legal obligation to safeguard others from harm while they are in your care, using your services, or exposed to your activities." From (HarperCollins) However the legal duty of care may be derived from a moral duty to care based on mutual respect and normative ideas of assisting those in need.

Vulnerability can be seen to be associated with particular weaknesses that can open an individual to greater risk of being manipulated (Rudinow, 1978). If I require chemotherapy, I am in some way vulnerable. Though I may be vulnerable, and I might not trust the chemotherapy nurse to administer me the right drugs, in such a situation it might be hard without such trust for me to accept therapy from that nurse. Perhaps I may not trust the nurse himself due to my biases, but perhaps I do trust my doctor who prescribed the therapy, and so I proceed with the infusions. Or perhaps I do not trust chemotherapy at all but go ahead as I feel compelled to by my partner whom I trust. That is, without a degree of trust in something, even if remote, therapy might not proceed. Alternatively, I may refuse to believe that I am vulnerable and might have difficulty in thinking that I have a need to trust what the chemotherapy nurse has to offer me. McLeod claims that,

‘a refusal to be vulnerable tends to undermine trust or prevents it from occurring at all’ (McLeod, 2011, p. 4).

Phillip Pettit writes that in trust you will, “make yourself vulnerable to the other person in some measure, to put yourself in a position where it is possible for the other person, so far as that person is a free agent, to harm you or yours” (Pettit, 1995, p. 208).

I consent to chemotherapy treatment on the understanding that, though I hope for assistance, I am asking a person to inject into me a substance that can kill me if it is the wrong type of chemotherapy drug or the wrong dose. Part of informed consent is understanding the risk and the nature of the vulnerability that I place myself in (Biros, 2018), with or without various types of care. The chemotherapy nurse has great power to harm me or to jeopardise my cancer therapy, and inevitably I am vulnerable to the

nurse as “I put my life in their hands”. Vulnerability and trust have associations not only in our direct interpersonal interactions, but on a group or societal level.

As a group who are aware of our potential vulnerability, we need trust in a pluralistic, co-deliberative society in order to live together, just as (I will argue, all) individuals need a level of trust and to be trusted, for our psychological wellbeing. To peacefully co-exist, individuals need to not only have a level of mutual respect for each other, but must also trust that other individuals will act in agreed ways or at least will not gratuitously harm others (Baier, 1986). In a modern tolerant pluralistic society one ought to be able to trust that one can walk on the street without being in fear of being molested for the colour of one’s skin (Ignatieff, 2016). Annette Baier writes on trust, “Trusting strangers will leave us alone should be construed as trusting them with the “care” of our valued autonomy”(Baier, 1986, p. 238).

Mutual respect, which I accept as a foundation of moral discourse, assumes that the other person is worthy of value simply because they are a human person basically like me or you (termed “recognition respect” (Darwall, 1977) and that they trust that the other person adopts certain attributes or will behave in particular ways (or will not behave in certain ways). A part of recognising that another person is like me might be to acknowledge that the other person has vulnerabilities as I do and that they are trusting that I will not use this awareness of their vulnerabilities against them.

It shows respect to listen to those who we trust to love us, or care for us, and we ought to trust that those who care for us have reasons to attempt dialogue with us. For a patient, or any person, to cut themselves off from others who are partial towards

them, not only may show distrust to carers or loved ones,²⁷⁵ but risks possible exposure to bias and influence of a kind that the patient may seek to avoid. It seems plausible to hold that being part of a family or “tribe” in some societies confers benefit for food, shelter and security. A “tribe” might also assist in gaining knowledge and beliefs or even a sense of identity. However, while the majority in a tribe may not be “right”, and past successes may not guarantee future successes; nevertheless there may be “safety in numbers” or in listening to the counsel of ones who we know care for us. On the individual level, a person needs to have trust (at some level) in themselves and in other people (or in what other people think or how they may act), or else that person will be very disturbed. Pamela Hieronymi supports the construal that part of what is to be healthy is being able to trust, when she says that, “a psychologically healthy person must be capable of trusting others” (Hieronymi, 2008, p. 213).

A patient once gave me an analogy that in psychosis they could not trust what was in their mind compared to what was outside. As an image, imagine the mind, as a nice country house with a garden and white picket fence around it. In psychosis one has no fence around the garden, and one cannot tell what thoughts are yours, and what thoughts belong to others. Psychosis is often horrible partly because it leads to an inability to trust what are one’s own thoughts rather than those of “others” who are in fact personifications of the patient’s hallucinations. In such a state a patient is left feeling vulnerable because they cannot tell what “they” authentically believe as distinct from what the hallucinations lead them to believe, what is real or who is real, or even if they are real. Psychosis may cut off a person’s the ability to trust others as psychosis

²⁷⁵ Such distrust may have negative social impacts that are important for a patient’s sense of identity and for their family.

may lead a person to distrust that another person is actually real, or that they mean what they say. In a paranoid state a person with psychosis might believe that the person they are speaking to is actually the instigator of their hallucinations or turning the world against them in some way. Trusting that one has a level of autonomy over one's own thought and destiny, seems to be an integral facet of personal psychological integrity.

Our freedom might be enhanced by our ability to trust in others. If a woman can trust others that she can walk on the street alone at night, she might feel an enhanced sense of freedom compared to if she fears being attacked at night. A paranoid person may feel free to relax with others and feel comfort in trusting that others mean them no harm and are not controlling them. By trusting an airline pilot, I may feel an enhanced sense of freedom in my ability to fly around the world with such ease. However, though trust might often enhance our sense of freedom, our freedom can also be limited should we feel that we have little option but to trust another person or system. Curtailed freedom can make us vulnerable to those we feel that we have little choice but to trust in order for us to achieve an objective, such as flying to another country.

For example, we (on some level) trust institutions, such as our nation's army because we have little choice in the matter (O'Neill, 2002). An infant trusts its mother to nurture as it has no other mother or choice. However, with such trust there is also vulnerability and the possibility of betrayal that in part explain why trust is so important in how we decide upon what is ethical behaviour. We feel particularly morally outraged when a mother betrays a child's trust, for example if a mother solicits for a child. Our outrage may be motivated not only by our view of the expected normative level of trust between

baby and mother but by our understanding of the level of reliance a vulnerable infant has upon its mother.²⁷⁶

In many aspects of health care, the patient is one who suffers. Though suffering does not inevitably make a patient vulnerable, pain, fear, and anxiety can make the patient more likely to have biases that lead them to need to trust a system or person where in other circumstances they may have been more cautious in their trust. In trust, there can be a level of vulnerability or weakness that, though not necessarily deleterious to the patient, reflects a need that the trustor has an expectation that the trusted may aid them. The “need” and “vulnerability” in health care differ from the character of need in companionship, or a consumer to vendor relationship. The times when we need to trust can make us vulnerable to who or what we trust in varying degrees as we release some of our power or freedom to the entrusted (Baier, 1986; Karen Jones, 1996). Patients are “those who suffer” and if a person suffers because they are in pain or their function is impaired, and because they lack the skills or knowledge to remediate a malady themselves, they may feel compelled to be vulnerable and “at the mercy of others for help”. In contrast the shopper is in a position of power over the shop assistant in a way the patient might not have power over the surgeon.²⁷⁷ The shopper may readily choose to walk into one shop or any other or to spend their money elsewhere; the shopper feels free to consume and spend as they will.

The potential vulnerability of ill health, in these examples leads to a limitation of

²⁷⁶ Oakley describes “perverse evil doing”(Harrosh & Crisp, 2018, pp. 103-126) in an example of which was Mengele’s Auschwitz twin experiments whereby the immoral behaviour perpetrated seemed particularly egregious as doctors flouted their duty to care as doctors for people in favour of perverse claims of scientific pursuits

²⁷⁷ The patient may have limited or no choice but to trust a surgeon as they didn’t choose to become acutely ill or have surgery, where-as the purchase of cosmetics may be a “discretionary spend” or part of the shopping process a person enjoys. The shopper may have chosen to walk into one shop or any other or to have spent their money elsewhere; the shopper feels free to consume and spend as they will. The shopper may have a perception of power that fits the narrative of credit card advertising.

power in *one facet* of a patient's life that is now shared with another person. Such reduction of power is not necessarily "good or bad" but is just a consideration that we ought to be aware of, in the way that such power shifts may plausibly be thought to alter the biases that people may have towards each other. If a patient gives some power to a health practitioner by trusting them, then the patient might be biased to more readily accept beliefs from the health practitioner, that the patient might otherwise have spent more time validating from other sources. For example, patients who have more trust in their doctors seem to refer to the internet less frequently than patients with less trust in their doctors (Lee & Hornik, 2009). Equally, a patient might resent what they see as a power imbalance and so might snub a health practitioner's advice, which can lead the patient to give inadequate consideration to salient evidence. In a patient-centred, shared decision-making process, such power issues are open for discussion and such discussion ought to be encouraged by an ethical health practitioner.

Ethical care requires caution by, and towards those who are charged with the power contingently lent them by a patient. Betrayal of trust from vulnerable patients in their time of need by health practitioners who abuse such entrusted power (to further the practitioners' interests over the needs over the patient's health care) is unjust and maleficent when such practitioners are ill qualified to have such power over another person in the first place. Reasonably, a qualified ethical doctor realizes the great weight of responsibility in being trusted and shares the patient's entrusted power with many other people as the doctor does not act alone but represents a large system of E.B.M. An ethical health practitioner should seek only qualified trust (i.e., conditional trust) and seeks that power remains with the patient and their family and friends or is shared with other health carers and the community. The rare health practitioner who

deceptively takes a patient's power, and trust, is reprehensible for shouldering such power that they are not responsible or qualified to hold. To dominate and hold power (for the sake of power) over someone who suffers and is vulnerable, is the antithesis of care and is morally reprehensible as it is so disrespectful. The individual person who suffers, is used as a means to the unethical practitioner selfishly attaining more power rather than rightfully being motivated by patient's best interests.

5.13 Betrayal of trust in health care can be particularly harmful to all parties.

A health practitioner can betray trust in at least several ways (1) when they set up an expectation in the patient that they are qualified in the area of patient expectations but they are not (2) when they falsely claim to be patient centred but they actually have personal or dogmatic motivations in offering care over patient centred motivations (3) when they purport to the patient that what they offer is health care, when actually it is instead, for example, part of a religious or cultural practice. There seems to be a particular injustice when the weak or vulnerable have their trust betrayed by those who are more powerful. It is unjust when the "trustor", stands to lose greatly or to lose what little hope they had, as they have invested trust in one more powerful than they, who acts from self-interest or is unqualified to be trusted. This seems related not only to how much the trustor stands to lose, but also relates to the level of expectation in the trustor of the trusted. The trusted person is placed in a position of power by the one who trusts them. and the betrayal of trust is an unjust usurping of power from the vulnerable.

Often in health care patients trust doctors with things that matter a lot to the patient (and have high risk to them), as contrasted with the purchase of eyeliner where the choice of best eyeliner would be great, but there are another twenty at home anyway.

It is less potentially harmful for a shop assistant to nudge a shopper to buy the eyeliner that increases the shop's profit, than it is for a surgeon to use a device that the surgeon has a financial interest in, over similar but better devices that rival the one the surgeon gains money from, as we reasonably expect that a surgeon puts patient's interest ahead of their own. The patient has a lot more to lose if there is a poor surgical outcome because their trust was betrayed, compared to just having one more eyeliner that they don't need. The value of what may be lost if trust is betrayed seems important, as Hieronymi argues,

the degree to which you trust a particular person to do a particular thing will vary inversely with the degree to which you must rely, for the motivation or justification of your trusting response, on reasons that concern the importance, or value, or necessity of having such a response (Hieronymi, 2008, p. 2013).

Additionally, generally speaking patients' expectations are reasonably higher for the surgeon's professional standards than for the shop assistant's. However a surgeon could breach such standards and wrongfully use the patient's ill-founded expectation of the surgeons degree of professionalism for the surgeons gain. A higher level of morality is expected of those in professional roles who serve us than a stranger in a shop assistant role. As Jones says.

When we trust professionals, from plumbers to physicians, we expect of them a technical competence (and minimal decency). However, the competence we expect in trusting need not be technical: when we trust a friend, the competence we expect them to display is a kind of moral competence. We expect a friend to understand loyalty, kindness, and generosity, and what they call for in various situations. (Karen Jones, 1996, p. 7)

Apart from emergency situations, modern health care has surgeons encouraging a relationship with the patient to foster substantial understanding and informed consent. The doctor in the I.D.D.P.R. (Emanuel & Emanuel, 1992) aspires to a moral standing of the health carer, sufficient to be qualified to guide a patient values as relevant to health care and as I discussed, akin to but not the same as friendship. Such moral standards are not required of casual strangers from whom I purchase cosmetics as substantial understanding and discussion of my values seems unlikely to occur in a consumerist encounter pertaining to the choice of an eyeliner.

A third way in which betrayal of trust is so harmful in health care is that breaching trust compromises professional standards and the personal integrity of the doctor. Professional codes of practice are long established in medicine. Colleges of speciality along with the broader community expect virtuous behaviour of doctors and expect doctors to act in their patients' interests. Indeed, often medicine is regarded as a vocation by the individual clinician and society (Imber, 2008). Being a doctor, a professional, can be part of what defines the doctor as a person and places the doctor in their relationships in the community. Doctors and their families often invest a lot of personal energy into attaining and maintaining the role of "doctor". The deliberate betrayal of professional values and one's patient's trust, could violate the doctor's personal integrity and defile an important part of who the doctor is. Furthermore, betrayal of patient trust and behaving in non-virtuous manner is harmful not only to the patient who stands the most to lose but is harmful to the image of the profession and the trust doctors need to carry out their work. Patients and doctors need qualified trust in qualified doctors, and betrayal of trust by doctors is a threat to the system of trust healthcare relies on. Immoral health carers prove they are not qualified to gain patient trust.

Professionalism may have aspects of detachment precisely to reduce harmful biases that threaten ethical care. Just as an ethical doctor is aware of professional boundaries of intimacy, so may such a doctor be sensitive to too much trust from patients, as such trust may bias what new evidence a patient appraises (Karen Jones, 1996). Trusting a health carer or health belief “too much” may yield bias in a patient that reduces their ability to appreciate the power of what or who influences them. Ethical health care operates in an environment of qualified trust as it attempts to be aware of bias and allow for bias in ethical decision making. Qualified trust may assist vulnerable patients regain some of their power by increasing opportunity to appraise their (and others) biases.

To conclude this section on the ethical use of trust in health care, I have argued that practitioners and patients ought to attend with great care to how and what they consider is trustworthy in how they come to make health care decisions. This is because, particularly in health care, what is entrusted might be precious to people who might be in a vulnerable state and importantly should their health suffer, others may also suffer if they are harmed, or opportunities for their improved health are lost. Betrayal of a patient’s trust by an unethical practitioner may be a particularly egregious form of harm to a patient. Furthermore, on the patient’s part, the way that the patient signals to others their trust might set up feelings of duty in their practitioners that the patient ought not to disregard. A patient ought not to signal trust to a practitioner in a manner that uses the practitioner as a mere instrument to a patient’s concealed intention. Disrespect might be shown by a patient to others who foreseeably will be harmed by the patient should the patient refuse to consider that the health belief that they trust might be untrustworthy. For these reasons, patients and doctors ought to have qualified trust in sources of health beliefs and practitioners rather than a degree

of faith in such sources of belief that may influence them to refuse to consider what their implicit biases might be or what others might wish to discuss with them. Qualified trust might be no less trustworthy than faith, but it can influence a practitioner or patient more receptive to considering the views of others who are owed a degree of respect.

Chapter 6: Conclusion.

This doctoral project has attempted to constructively address a facet of my medical practice that I find particularly confronting; namely when a patient and I have a fundamental disagreement about a matter of their health care, that is based upon differences in what we both consider would be the best health decision for the patient in their situation.

A doctor or patient cannot plausibly deny that, at least in matters of health and health care, there is much uncertainty in how matters of health can change, and that just as physical bodies are fallible, so too we are fallible in seeking to make well-founded health-related decisions, and in considering how we might affect others we care for or who care for us. I have argued that in health care, doctors and patient ought to adopt a fallibilist attitude, and by being humble, ought to be self-reflective and reasonably tolerant of a plurality of views. While there is no certainty that we will develop better-founded beliefs by appraising the views of (many) others, with increased numbers of people and a wider net of evidence we might well be more successful at gaining new understandings, and in attaining more credible evidence due to the numbers of people working together who are sharing their successes and failures.

I have argued for a novel ethical defence of the ideal process of E.B.M. that rests on an attitude of fallibilism. In acknowledging their fallibility, those who refer to the process of E.B.M. - the doctor, patient and those who develop and sustain the process- may act ethically towards one another in the way that they ideally should attend to one another's beliefs and values, and thereby show a degree of recognition respect towards one another. The requirement for co-deliberation seen in Scanlon's contractualism, in the I.D.D.P.R., and the ideal the process or E.B.M., can be seen as a natural fit with one another into a schema of three linked constructs that a doctor and patient can use to determine how they ought to relate to each other, based on what they determine they owe to each other.

Reflecting on a critical appraisal of the nature of hope and trust in health care, I examined the unethical use of hope and trust in health care in real and fictitious clinical cases. I sought to examine how a doctor or patient's relationship with each other, or the patient's loved ones interacts with what the patient hopes for and trusts in. Before arguing for why hope was wrongly used or trust was betrayed in representative fictitious clinical cases, I developed a schema of what the patient and doctor relationship ought to aspire to. I do not claim that what I came up with is perfect or always applicable. However, the schema can be referred to as an instrument that may assist a doctor and patient to decide how they ought to relate to each other, in the context of the professional setting of the patient coming to the doctor for a purpose, and the doctor, while in that role, representing certain expectations of what doctors ought to be. Within this relationship, within whatever parameters are set for the boundaries of the relationship, both doctor and patient cannot deny that they owe it to each other to recognise that both are feeling people who warrant a level of respect from one another.

While the emotions of hope and trust seem at play in most interpersonal relationships, these emotions are undeniably important for health care and the individual doctor-patient relationship. I have struggled to understand why some patients and doctors have trusted certain health practitioners or processes, or have held hopes about people or things that seem to me to be unjustifiable, both morally and epistemically. I have sought to understand more about the nature of hope in trust in health care, and I have argued that due to the possibly profound effects of hope and trust in health care, both doctors and patients ought to be responsive to being reflective, not just in what they have hopes about and trust, but in how they come to hope or trust in a health matter. In both hope and trust in health care we all ought to adopt a fallibilist attitude, and ought to be reserved in how and what we trust, in contrast to being more dogmatic in holding unreserved faith or more radical hope in someone or something.

As a doctor, I initially consider that a patient's hope for a health care matter is supported by ill-founded beliefs, or that the process or person that provides grounds for that hope are untrustworthy, or that the patient ought to consider how what they hope for can place unfair burdens on others. A patient may believe the same about what I hope for in their health care. By being humble and adopting a fallibilist attitude, we can be respectful to each other, and can engage in co-deliberation to determine what we both cannot reasonably reject should be tolerated or not tolerated in relation to what their health care should be. I ought not to treat a patient in certain well recognised ways commonly discussed the field of bioethics²⁷⁸, so too a patient ought not to treat me in certain ways as they owe me a degree of recognition respect, at

²⁷⁸ For example, by placing my interests ahead of the patient's, disrespecting a patient's autonomy, and the principle of informed consent etc.

least as a person. A patient who adopts a fallibilist attitude and comes to the doctor-patient relationship as I do, being guided by the schema of the three constructs, ought to not treat me like a “moral other” and reject outright my attempts at co-deliberation about my belief that they have not properly considered how their health decision might harm themselves, me, or might harm their loved ones. If the patient ‘locks me out’ by refusing to attend to my view in the manner of the schema I thought we had agreed upon, or if I do the same to them, the doctor-patient relationship become less than ideal and might not continue.

In ethical health care both patients and doctors ought to adopt a fallibilist attitude, as they owe it to each other to acknowledge that they both might err, and they should show respect for the other by attending to each other’s views. The ideal process of E.B.M. is based on fallibilism and facilitates those involved in health care to have qualified trust in processes or qualified providers, and to find well-grounded objects of hope for health care that they can justify to one another.

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