Autonomy and Well-Being in the Context of Cancer Care

By Katrina O'Keefe

Submitted to the University of Nottingham for the degree of PhD of Philosophy

2019

Acknowledgements

Throughout the many stages of writing this thesis I received many comments and suggestions. I would like to thank those individuals who have helped me to complete this project. I want to thank both of my supervisors Dr. Christopher Woodard and Dr. Neil Sinclair for all of their helpful comments and suggestions through the many stages of writing this thesis. My examiners Dr. Ian James Kidd and Dr. David Shaw gave me very detailed and constructive comments, which helped to make this project and the arguments within more refined and cohesive. I also want to thank those who attended the Post graduate Research Seminars for the helpful questions, comments, and suggestions.

I would also like to thank my family for being so supportive of my goal. Their contributions to this project have really made it possible. My parents Sheila O'Keefe and William Code did everything they could to help me to achieve my goal, including providing an abundance of moral support. My brother Trystin Code-O'Keefe was always available to talk and helped me to keep my motivation up when working on the more tedious aspects of this project, like editing. Lastly I would like to thank my grandfather, Jack O'Keefe, for always encouraging me. Without his influence I don't know whether I would have ever considered taking on the challenge of attempting and completing a PhD.

Table of Contents

Acknowledgements 2
Introduction 7

Health, Medicine, and Cancer Care 26

I - Health 28
I.I - Methodology 29
I.II – Theories of Health 38
I.III – Health as Absence 42
I.IV – Health as Well-being 43
I.V – Health as Biological Functioning 48
I.VI – Health as Fulfilling Social Roles 55
I.VII – Health as Being in the World 57
I.VIII – The Combination Theory of Health 60
II – The Relationship Between Health and Medicine 76
III – Cancer Care 83
IV – Conclusion 85
Health and Well-being 87

I – Beneficence and Nonmaleficence 91
II – Well-Being 98
II.I – Hedonist Theories of Well-Being 99
II.II – Desire Satisfaction Theories of Well-Being 102
II.III – Objective List Theories of Well-Being 111
II.IV – Hybrid Theories of Well-Being 114
III – Well-being and Health 118
IV –Health and Well-being: QALYs and Disability Studies 129
V – Conclusion 133
Autonomy 136

I – Informed Consent 138
II – Accounts of Autonomy 152
II.I – Motivations 155
II.II – Reason and Rationality 163
II.III – Individuality 171
III – Synthesis 178
IV –Autonomy and Health 181

V –Epistemic Injustice and Autonomy 183
VI – Conclusion 188
End of Life 192

I – The Standard View 196
II – The First Interpretation 212
II.I –Achievement of Criteria Negatively Impact Well-Being and Autonomy 213
II.II – Identification and Counterintuitive Implications 218
III – The Second Interpretation 222
IV – Some Other Considerations 224
V –Assisted Dying 225
VI – Conclusion 240
Genetic Testing 243

I - Genetic Testing for an Inherited Susceptibility to Cancer 249
I.I – Physician Recommendation 250
I.II – Procedures 250
II – Understanding the Risk 258
III – Reasons for Seeking Genetic Testing 262
IV - What are the Benefits? 265
IV.I – The Advantages of Knowing 265
IV.II – Career and Hobbies 267
IV.III – Reproductive Choices 268
IV.IV – Risk, Surveillance, and Prevention 269
IV.V – Family Relations 270
IV.VI – Perception by Others 271
V – What are the Costs? 272
V.I – The Disadvantages of Knowing 272
V.II – Career and Hobbies 273
V.III – Reproductive Choices 274
V.IV – Risk, Surveillance, and Prevention 276
V.V – Family Relations 279
V.VI – Perception by Others 281
V.VII – Perception of One's Environment 284
VI – Respecting Autonomy: What does it mean? Whose should we be respecting? 286
VI.I – Whose Results are They? 287

VI.II – Accurate Risk Assessment 289
VI.III – Respecting Autonomy and Transformative Experience 291
VII – Considerations in Favour of Offering Genetic Testing 300
VIII - Conclusion 307
Conclusion 309

Bibliography 323

Printed Sources 323
Websites and Encyclopaedia Entries 328

List of Figures

Figure 1 ……251

Figure 2 ……253

Figure 3 ……254

Introduction

Cancer touches many of our lives in many different ways. We are patients, survivors, family members, caregivers, and friends. Cancer is a generic term applied to a group of over 200 disease that share common characteristics. One common feature among all of these diseases is the unregulated growth and spread of cells to different areas of the body.[1] Cancer care covers a wide range of treatments and services ranging from surgery, chemotherapy, radiation, supportive care, symptom management and palliative care.[2] This project investigates the tension or apparent tension between promotion of patient well-being and respect for patient autonomy in the context of cancer care. To do this I intend to investigate the relationship between these two aims and how they weigh up to one another in the context of cancer care. The research I have conducted to engage in this investigation has indicated that many of the sources available focus primarily on one or the other of these aims, while the other aim, if addressed, is secondary to their purpose. This being the case the matters that are addressed and the arguments that are presented are through the lens of one aim, even in instances when the second aim is discussed. For instance, one example appears in chapter four where I will look at a study conducted by Gert Othluis and Wim Dekkers which investigates well-being and quality of life in palliative care.[3] This study highlights the importance of

[1] Gabriel, 2004, 3.
[2] Zahedi and Larijani, 2007, 17.
[3] This study interviewed "nineteen palliative care professionals from three different settings." The interviews were guided using a semi-structured list of topics.

the patient's participation in planning their end of life care and how this participation contributes to the patient's well-being. Participation in planning one's end of life treatment and care is important for the patient to exercise their autonomy, but Othluis' and Dekkers' study focuses on well-being, so this participation is viewed through the lens of its contribution to well-being. On some accounts of well-being autonomy may be included as a constituent of well-being, but this study made no claims as to whether autonomy is a constituent of well-being.

This investigation will be an in depth look at both of these aims and the relationship between them. Cancer care has a wide scope—including testing, treatment, end of life care, and remission. How these aims are addressed can differ between these different contexts within cancer care. If there were an overarching guiding principle, which gives one of these aims preference in times when they conflict, things would be easier. However, I think that an overarching principle of this kind is unlikely. But understanding the relationship between these aims and how our considerations for these aims interact and play out in different contexts may help to provide some guidance in situations when they do conflict.

There can be a tension or conflict between respecting patient autonomy and promoting patient well-being in very obvious ways. For example, these concerns may conflict if an individual refuses treatment, or the physician is unsure whether the patient understands the risks associated with a potentially beneficial treatment or procedure well enough to give an informed consent for that treatment or procedure. However, respecting

---

Othluis and Dekkers, 2005, 311.

patient autonomy and promoting patient well-being can appear to be in tension in less obvious ways as well. Genetic testing is an example of a time when the tension or conflict may be less obvious. There are ways that this type of testing can impact on the tested individual's well-being and autonomy that are not immediately obvious, so in choosing to be tested the conflict between respecting autonomy and promoting well-being is also not obvious. By looking into these less obvious cases we can gain a better understanding of the relationship between these two aims and how the importance of each compares with the other in different situations.

There are four principles of biomedical ethics outlined by Tom L. Beauchamp and James F. Childress: beneficence, nonmaleficence, respect for autonomy, and justice.[4] This project will deal primarily with three of these principles: beneficence, nonmaleficence, and respect for autonomy. Autonomy is explicitly mentioned in the title of this project, but the other two principles are not. Our concerns for patient well-being are standardly expressed through a combination of beneficence and nonmaleficence; our duties to benefit patients and duties not to harm them. I will argue that at the base of these two duties is a concern for well-being. In chapter two I will argue that in the field of medicine we promote patient well-being primarily through concerns for people's health. I will argue that the focus on health is appropriate because of the knowledge and skills developed by professionals in medicine, so the means by which professionals in this field should promote well-being is through the promotion of health. However, in chapter five I will argue that when we are determining whether to include tests, treatments, or

[4] Beauchamp and Childress, 1994, 120-394.

procedures as options available to patients within medicine, we should take into consideration the impact that these tests, treatments, and procedures will have on well-being more generally and not simply focus on the possible health benefits that the test, treatment, or procedure might provide. I do not believe that these two arguments conflict as medicine and medical science is concerned with health, but determining whether any particular test, treatment, or procedure should be available is a matter of policy and requires broader considerations.

To attempt to address these questions the structure of this project will begin by dedicating chapters two through four to the theoretical background work that will be needed to move forward. Chapters five and six will look at two examples to investigate the relative importance of these two values. The aim is to determine whether one of these values is more important in both cases. If it were to turn out that either promoting well-being or respecting autonomy should be given more weight in both of these cases, this could support the claim that an overarching principle could be developed to give guidance for other cases. However, the converse could also be true: if the conclusions of the investigation into each case do not indicate a higher importance for the same value, then it might be the case that neither promoting well-being nor respecting autonomy should be given more weight as a general rule. I believe that the second outcome is more likely, but this investigation can still provide us with a better understanding of these aims and the considerations that play an important role when we are trying to determine how to proceed when there is a conflict or tension between both promoting well-being and respecting autonomy. The first example looks at end of life care, while the

second looks at genetic screening for an inherited susceptibility to cancer. I chose these two examples because it is not immediately obvious how promoting well-being and respecting autonomy can be in tension in these cases. Since the tension is not obvious I think that investigating it in these cases can provide insight into the possible tension between promoting well-being and respecting autonomy and how to accommodate this tension.

I will argue that neither autonomy nor well-being holds a privileged position in our considerations of what to do. I will argue that we should respect autonomy as much as possible and provide individuals with the information that they need to exercise their autonomy in uncertain situations. We should also promote patient well-being as much as possible. Promoting patient well-being can refer to concern for the well-being of a particular individual, but it can also be done in a more abstract way such as determining what we make available for people to use. Both of these aims should play a role in our considerations or deliberations about what types of tests, treatments, and procedures should be offered through medicine and how they should be offered to patients. For example, in chapter five I will argue that pre-testing genetic counselling is an important part of the genetic testing process, both because I think that it can mitigate some of the negative impacts on well-being that tested individuals may experience, but also because I think that it is the best way to ensure that individuals seeking testing are giving an informed consent to undergo testing.

To argue for these conclusions I will use a mixture of methods. Conceptual analysis will be employed at various points in this project. I will argue that our theoretical concepts should fit well with our ordinary notions. They

should explain why we assign the value that we do, and they must be coherent. Moral intuitions play a role in this project and will also often be the base or starting point for the arguments that are presented throughout this project. I think that moral intuitions can play an important role in gaining moral knowledge. Some argue that we can be justified in claiming that moral intuitions are a source of moral knowledge and this justification can be found in psychology. Thomas W. Smythe and Thomas G. Evans in their paper "Intuitions as a Basic Source of Moral Knowledge" argue that you can find support for the claim that moral intuitions are a genuine source of moral knowledge based on the work by psychologist Marc Hauser.[5] They argue that moral intuitions are "noninferential nonsensuous perception"[6] and the psychological processes involved in these intuitions are similar to other psychological processes that we deem to be justified sources of knowledge or ways of forming beliefs.[7] Along with the support provided through psychology, Smythe and Evans, also argue that there tends to be a consensus, across cultures and religions, on many moral intuitions. These intuitions are commonly accepted as moral precepts. They argue that this acceptance of moral intuitions shows that they are prevalent sources of moral knowledge.[8] These intuitions are a source of moral knowledge and can be the basis for philosophical reflection and analysis.

Smythe and Evans are not the only ones to link moral intuitions with psychological processes and highlight the similarities between moral intuitions and other processes that we deem to be justifiable sources of

[5] Smythe and Evans, 2007, 236-238.
[6] Smythe and Evans, 2007, 242.
[7] Smythe and Evans, 2007, 242.
[8] Smythe and Evans, 2007, 243.

knowledge. However, I think that these arguments support my use of moral intuitions as a starting point for reflection and analysis in this project. I think that moral intuitions can help us to spot when different theories or solutions might be missing the mark, but it is important to tease out why we have a particular intuition. We may have an intuition that a particular theory is incorrect, but analysis and reflection may be required to determine precisely why this is.

I aim to frame the arguments and examples presented in this project in a realistic way so that we can get at the crux of the issues in a way that is accessible, in the sense that the reader is not required to have a strong philosophical background to engage fruitfully with the arguments and examples presented, and relates to how things are.[9] Part of this framing uses current studies from different disciplines to shape and justify the way I will set out the arguments. Not only do these studies help to frame the examples and arguments realistically, the studies also help to illustrate the connections between theories present in the literature and how they influence professionals working in the field. I think that it is important to highlight these influences because it shows that the theories produced and discussed within philosophy are not merely an intellectual pursuit, but that they are useful in practice and that they have influence outside of being an intellectual endeavour. I want to show the tangible links between the academic literature and practice, as well as to demonstrate that the theories put forth in the

[9] This simply means that individuals in other disciplines within the university may be interested in accessing this thesis once it has been uploaded into the database, and I wanted to make sure it was written in such a way that it could be useful to others.

literature are not a purely academic endeavour, but have influences outside of academia.

While it may be the case that those producing the academic literature and those working in the field—or teaching those who work in the field—are using and are influenced by the same theories, the dissemination of these theories may differ. For instance, in the 'good death' literature you can find what I will call a standard view that reoccurs quite consistently. In practice you can see its influences on professionals' expressed perceptions and how they interact with their patients, without those professionals explicitly advocating adherence to the standard view, or acknowledging the theory at all.

In chapter one I address the question: what is health? This chapter involves conceptual analysis, investigating five theories of health and comparing them to our ordinary notions of health to see how well they capture what it is we are referring to when we are applying our concept of health in our day-to-day life. The theories of health that are considered are: the absence of disease, illness, and injury; the World Health Organisation's definition of health; the biological functioning theory of health; the social roles theory of health; and a phenomenological theory of health. An adequate theory of health should fit well with our ordinary notions of health, explain why we value health, and be coherent. I will argue that the five theories of health that are considered fail on these criteria and I will propose a theory of health that I believe does a better job.

The theory of health that I will propose combines the absence of disease, illness, and injury with a selection of capabilities or capacities that better accommodates our ordinary notions of health. I argue that this theory does a better job of explaining how we think of health and how we use our concept of health in our day-to-day lives, and I use several examples to demonstrate this. Our concept of health influences medicine. These influences include what types of things we research, what is offered through treatment, how we approach providing patient care, and what types of knowledge we view as being important or contributing within the field. This chapter will also consider what the goals of medicine are and how these different goals would shape how we practice medicine. I will argue that the goal of medicine is not merely restorative, preventative, or promotional but a combination of these. Medicine does not aim merely to restore individuals to their previous state of health; nor does it focus solely on preventative medicines so as to help people to avoid becoming ill or needing treatment; nor does it focus solely on promoting patient health through research into ways of living that enhance or encourage health, such as diet and exercise. Instead, medicine endorses all three. Medicine and medical research aims to restore patients' lost health as much as possible, to prevent patients from becoming ill, and to aid patients in promoting their health. The preventative and promotional aspects of health aim to help patients to avoid a reduction in health that will likely require treatment.

The second chapter will discuss well-being and the relationship between well-being and health. While medicine focuses mainly on health, I will argue that if we look at the principles of beneficence and nonmaleficence we find a

concern for well-being more generally. Well-being is most often defined as what makes a person's life go well for them. When looking at our duty not to harm others (nonmaleficence) what we are doing is making sure we are not reducing the individual's well-being through our actions towards them. A similar case can be made for our duty to help or benefit others (beneficence), since helping someone generally aids in making their life go well for them. While duties of beneficence are often not regarded as obligatory in day-to-day life they are regarded as obligatory in medicine. The reason that we think that medical professionals are most suited to promoting well-being through health, and that this focus on health is justified, is because medical professionals possess a vast amount of in depth knowledge about health and the body and they have a specific skill set aimed at addressing issues related to health and the body. However, the relationship between health and well-being is complex and they are intimately intertwined. To show this I will discuss different types of theories of well-being. The types of theories that will be discussed in this chapter are hedonist theories, desire satisfaction theories, objective list theories, and hybrid theories of well-being. Particular theories may differ, but they have general characteristics depending on the type of theory they fall under.

The goal of this chapter will be to show that the relationship between health and well-being is complex and intertwined no matter which theory of well-being one subscribes to. The relationship between health and well-being is more complex than the limitations that ill health can put on the individual's ability to satisfy desires, or to obtain some or any of the constituents of wellbeing. Nor does the relationship hinge only on the pain or discomfort

associated with ill health. The relationship between health and well-being is much more complex than this, and health can have far reaching implications for the individual's level of well-being. After the analysis of the relationship between health and well-being I discuss quality adjusted life years (QALYs) and disability studies; both of these make some statement about the relationship between health and well-being. QALYs are health measures which attempt to measure the amount of quality of life or well-being lost by a particular health state, by definition there is an assumption that ill-health will have a negative impact on the individual's quality of life or well-being. I will also look at disability studies which find that chronic illness or disability does not have a significant reduction in subjective well-being.

Here it is also important to note that when I introduced this project above I mentioned that I am going to investigate the tension or apparent tension between promotion of patient well-being and respect for patient autonomy. In chapter two several different theories of well-being will be discussed. Some of these theories claim that there are multiple constituents of well-being. If autonomy is one of these constituents, then any tension between promotion of well-being and respect for autonomy would only be an apparent tension because the tension would not be between two separate values (promoting well-being and respecting autonomy), but between different constituents of a single value, well-being. This type of theory of well-being may have a method for dealing with conflicting constituents in place within the theory. However, if this is not the case, then some sort of guidance will be needed to address conflicts between these constituents. As I am not ruling out that autonomy may be a constituent of well-being I will

concede that the tension may only be an apparent tension between two values. Since this chapter will demonstrate that the relationship between health and well-being is complex and intimately intertwined on all these types of theories of well-being, I do not think that it is necessary to take a stance on which theory of well-being is correct in order to make the arguments required later in this project. Not subscribing to a particular theory of well-being helps to make my arguments more widely applicable because they can apply to the different types of theories discussed.

Chapter three will look at respect for autonomy. This chapter will begin by arguing that the moral significance of informed consent lies in the fact that the consent is an expression of the individual exercising their personal autonomy. This is contrary to what is claimed by Ruth R. Faden and Tom L. Beauchamp.[10] They argue that the moral significance of informed consent lies in the consent being a particular kind of autonomous action. I will argue that Beauchamp and Faden do not give enough consideration to what we are trying to identify with competency requirements in our informed consent procedures. When we make competency requirements we are attempting to identify features of persons that show that the person is autonomous. Because of this, I claim, we are concerned with the autonomy of persons and not strictly with whether the action is autonomous.

I will then discuss different theories of personal autonomy. I use Ben Colburn's categorisation which, categorise the different types of theories by identifying the core feature of each theory that makes it different from other theories. Ben Colburn argues for this type of categorisation in his book

[10] Faden and Beauchamp, 1986, 235-297.

Autonomy and Liberalism.[11] I will also outline a specific example of each type of theory to help with my analysis. The categories that Colburn suggests are motivations, reason and rationality, and individuality. I will use Gerald Dworkin's theory of autonomy for the motivations category. David A.J. Richards' theory is an example of a theory that holds reason and rationality to be core. For the final category I will use the theory that Ben Colburn proposes in his book, which focuses on life plans and the importance of the individual being "a (part) author of their own life"[12]. I will argue that David A.J. Richards' theory of autonomy or one similar to it is the most apt theory of autonomy.[13] A theory of autonomy that identifies a set of complex capacities that are constitutive of autonomy better fits with current studies in psychology. This type of theory can also better explain how autonomy develops over time and how some people may never be autonomous. Developmental psychology is an excellent tool for understanding how people develop different capacities as they grow. Using this tool we can better adapt our competency requirements to ensure that they capture the highest number of consents that are valid and exclude those consents that are not valid. An account of personal autonomy like Richards' can also better explain how our health can impact on our ability to exercise our autonomy and how we may no longer be autonomous towards the end of our life, as we may lose some of the complex capacities constitutive of autonomy during the dying process. I think that a theory like Richards' also picks out the same kinds of capacities that we are trying to pick out with our competency requirement. This being the case I think that a theory of autonomy like Richards' better explains the

[11] Colburn, 2010, 4-20.
[12] Colburn, 2010, 12.
[13] Richards, 1981, 3-20.

moral significance of informed consent. After this analysis I discuss epistemic injustice and how this can cause problems for patients exercising their autonomy. In the previous two chapters I flag up some epistemic concerns that are best addressed in this chapter because of the moral significance of informed consent and the arguments presented against the ideal of autonomy held in medicine.

Chapter four will deal with end of life care and the conception of a good death. A good death is one that goes well for the dying individual. A prevalent view of what is required for achieving a 'good death' indicates a list of criteria such as these: being self-aware, being aware that you are dying, being surrounded by friends and loved ones, taking part in planning your end of life care, and being as free as possible from physical and emotional pain and distress. Throughout the chapter I will call this view the 'standard view' of a good death. I will use studies conducted in palliative and hospice care to support my claim that this conception of a good death is prevalent in both theory and practice. This theory of a good death influences how professionals in palliative care treat their patients and the patient's family.

I will argue that if the standard view is seen as a list of requirements for a 'good death', then it is problematic—since achieving these requirements may not promote the patient's well-being or respect their autonomy at the end of their life. I will also argue that if the standard view is seen as a list of criteria, then the standard view is counterintuitive. The standard view is counterintuitive because of who it excludes from achieving a 'good death.' The awareness that is required to fulfil this criterion is not the sort of intellectual awareness that on might possess about how everyone dies, but

that awareness that they have entered into the dying process and their time is drawing near. If one remains relatively healthy into their old age, even if they acknowledge that they are getting older and their life will be drawing to a close and the older they get the sooner that close will be, they can still lack the awareness that they are dying or have entered into the dying process that appears to be required by the standard view. The standard view narrows the set of people who can achieve a good death to those who are terminally ill or can know that they have entered into the dying process. This means that those individuals who make it into old age and stay relatively healthy until their deaths, on this view, cannot achieve a 'good death'.

I will argue that a 'good death', in the sense that it is a death that goes well for the dying individual, is one that promotes the dying individual's well-being as much as possible and respects their autonomy for as long as possible. However, if the standard view is interpreted not as a list of criteria of a 'good death', but instead as a list of general recommendations or suggestions for promoting a good death, then it is not problematic. If this is the case, then the standard view fits in well with the idea that a good death is one that promotes the dying individual's well-being as much as possible and respects their autonomy for as long as possible. In this chapter I present some arguments for the moral permissibility of assisted dying and assisted dying is compatible with the conception of a 'good death' put forward in this chapter. In the case of end of life care I think that autonomy should be given a little bit more weight than promoting well-being because I think that it is important for the individual to have some control over how they end their life. This can be done by respecting the wishes they express when they discuss their end of

life care or compose an advanced directive. These plans are made with their preferences and values in mind. However, this can be difficult because sometimes things do not go as planned and after circumstances have changed the individual may no longer be capable of exercising their autonomy.

Chapter five will move from the end of the progression of cancer towards concerns people may have before they become cancer patients. This chapter will investigate well-being and autonomy in genetic testing for an inherited susceptibility to cancer. The chapter will begin by discussing what genetic testing for an inherited susceptibility to cancer can do and the limitations of this type of testing. It discusses how people can go about getting testing and the procedures involved in getting testing. In the first portion of the chapter I will discuss genetic counselling and which methods of testing include genetic counselling. The first portion of the chapter is very important for later arguments about autonomy, because genetic testing in many cases is a transformative experience in L. A. Paul's sense.[14] As with other transformative experiences, there is a question about how to understand respect for autonomous decision-making. Before moving forward to discuss the possible impacts that this type of testing can have on the tested individual's well-being and autonomy, I will discuss how the increased risk of developing cancer for those with an inherited susceptibility to cancer may look when compared to the risk of developing cancer for those without an inherited susceptibility. This exercise is meant to give the reader an idea of how the risk might work and how this may influence the reasons that an individual with such a susceptibility would have for making appropriate

[14] Paul, 2014.

changes. The impact on well-being and autonomy that one experiences may also depend on how the increased risk associated with an inherited susceptibility works.

Once the procedures, risk, and reasons for testing are discussed I will move forward to look at both the positive and negative impacts of this type of testing on the well-being and autonomy of the tested individual. Genetic testing of this kind can have an impact on many areas of the tested individual's life. The knowledge that one does or does not have an inherited susceptibility can have far-reaching implications for that individual: on their career and hobbies, their reproductive choices, and their relationship with others. This is why it is so important that the individual has access to pre-screening genetic counselling. Understanding the possible consequences of this type of testing is just as important or more important for choosing to undergo testing, than understanding the results of the test. Pre-screening genetic counselling is also very important because we do not know how this information may change us and our values until after the test. In these kinds of transformative experiences it can be very difficult to exercise our autonomy, and to respect the chooser's autonomy. By providing pre-screening genetic counselling we are making sure that the individuals who are seeking testing are aware that this decision can change them in ways that they may not be able to anticipate, and that they need to make a decision as to whether they are willing to be changed in these ways. I will argue that pre-screening genetic counselling is the best way to respect the autonomy of the individual seeking testing.

I will conclude this chapter by arguing that before we offer genetic testing of this kind we should take into consideration not just the possible health benefits of early detection, but also how this type of testing can impact on the well-being and autonomy of the individuals seeking testing. This is especially important because cancer is a multifactorial disease, meaning that there is an interaction between genetic and environmental factors for this disease to develop, and those who have a genetically inherited susceptibility to cancer may never develop cancer, but will still be impacted by this type of testing. I will argue that this is another reason why we should not offer this type of testing without pre-screening genetic counselling. Genetic counselling can help people to understand the possible consequences that this type of testing can have and may also be able to mitigate some of the more negative ways that this type of testing can impact on the individual's well-being and autonomy. So in the case of genetic testing of this kind, concerns for well-being and autonomy should come prior to offering this service to anyone, and steps should be taken to attempt to reduce the possible negative impact the service may have.

The conclusion of this project will be that there is no general priority rule governing the relative importance of promoting well-being or respecting autonomy across situations in cancer care. On different occasions it is appropriate to place different weights on these two considerations. While concerns for well-being should be taken into consideration when determining what types of test, treatments, and procedures we offer as possible options for people in general, it is also important to identify whether offering the tests, treatments, and procedures can have implications for autonomy and

informed consent. As I will show from the examples provided, respecting patient autonomy in some cases can be difficult because things did not go as planned and the individual may no longer be capable of exercising their autonomy, or the situation might be such that exercising one's autonomy in situations that are transformative can be difficult. I suspect that these concerns are mirrored in other areas of cancer care that are not discussed in this project. In these cases, knowing how to respect patient autonomy may be difficult and we may think that the best thing to do in these situations is to promote the patient's well-being. However, this may be giving undue weight to the promotion of well-being. The fact that it may be difficult to respect autonomy does not imply that we should then prioritize the aim that is easier to achieve. It is important to recognise our limitations while still attempting to respect autonomy and promote well-being as best we can.

Health, Medicine, and Cancer Care

This chapter is going to provide a backdrop for our investigation into how our concerns for the promotion of patient well-being and respect for patient autonomy play out in the context of cancer care. Before we can begin it is important to address three topics; health, the relationship between health and medicine, and cancer care. What is health? How do we determine what makes for a successful theory of health? Our theory of health influences medicine and the medical sciences. It plays a role in what gets included in treatment and what avenues of investigation and enquiry fall under the scope of medical science and what types of knowledge are appropriate for the field. This chapter argues that the aims of medicine are not solely focused on restoring one's health, but include preventative and promotional aspects as well. The inclusion of these three different aims indicates a more inclusive theory of health. Lastly this chapter will look at cancer care more specifically. There has been a recent shift in cancer care from a strictly curative focus to one that is more inclusive. This recent shift in cancer care points to a concern for the general health promotion of patients. This shift in cancer care better highlights the aims of medicine.

The first section of this chapter will look at the question: what is health? To answer this question we must first determine what the criteria are for evaluating whether a theory of health is successful or not. In this section I argue that Daniel M. Haybron's criteria for evaluating a theory of happiness

can be applied to evaluating a theory of health.[15] Haybron presents four criteria for evaluating and constructing a theory of happiness and these criteria map onto a theory of health quite well. After outlining my explanation of the methodology I will use to evaluate theories of health, I present six theories of health. The first five are theories of health that can be found in the literature today. I argue that all four of these theories fail to meet the criteria for a successful theory of health. These theories are: health is the absence of disease, illness, and injury; health is a state of complete physical, mental, and social well-being, not just the absence of disease and infirmity; health is the normal biological functioning of the organism; health is the ability to fulfil one's social roles; and health is a homelike being in the world. I will then propose a theory of health that better meets the criteria for a successful theory of health. This theory is a combination of the absence of disease, illness, and injury and the presence of capabilities to function.

The concept of health is intricately intertwined with the study and practice of medicine. In the second section I will argue that the aims of medicine are focused on general health promotion, meaning that the aims include restorative, preventative, and promotional features. A theory of health that is a combination of capabilities and the absence of disease, illness, and injury can better support the inclusion of the restorative, preventative, and promotional features which we expect from medicine, than the other theories of health that will be presented in this chapter. I think that the combination theory's ability to fit well with the goals of medicine and our expectations of

[15] Haybron, 2008, 48-55.

what medicine should include helps to strengthen the application of the theory.

The third and final section of this chapter looks at the recent shift in cancer care from a strictly curative focus to a focus which is more inclusive and aims at general health promotion. The inclusion of not only cancer treatments, but screening, supportive care, and palliative care under the heading of cancer care demonstrates a commitment to promoting the general health of patients. This shift in cancer care takes in more of the aims of medicine than simply aiming to restore patients' health and provides further support for the arguments provided in section two. In this section I also introduce the shared decision-making model used in cancer care; this will provide a framework for later discussions in chapter three about informed consent.

This chapter will conclude by arguing that the combination theory of health, while incomplete, is a successful theory of health that can better explain the aims of medicine than the other theories presented. The recent shift in cancer care further justifies the arguments presented about the aims of medicine being restorative, preventative, and promotional. The conclusions will be important for the next chapter on well-being where I argue that the relationship between health and well-being is complex and intertwined no matter which type of theory of well-being one subscribes to. I will argue that medics promote patient well-being through the patient's health.

I - Health

Health can positively and negatively impact on an individual's well-being and plays a key role in medicine, but what is health? We apply the concept of

health in our day-to-day life, but when asked precisely what we mean by 'health' we often have a difficult time answering the question. Since health plays an important role in both well-being and medicine, a brief look into different theories of health will be beneficial before we proceed into a more in depth look at well-being in the next chapter.

I.I - Methodology

In order to answer the question: what is health; we must first determine what would make a theory of health successful. A philosophical theory of health is important because it enables us to solve disputes and engage in discourse about health without merely speaking past each other. Our theory of health shapes how we think about medicine, has an influence on our daily lives, and it can influence how we interact with other people.

What features must a theory of health have in order for it to be a successful theory or more successful in comparison with other theories? I would argue that a successful theory of health is required to fulfil four criteria: it must fit well with our day-to-day application of our concept of health, the theory must be coherent, a successful theory of health must be able to adequately explain why we value health, and a successful theory of health must be theoretically and practically applicable.[16] The four criteria that I argue we should use to formulate and evaluate different theories of health have been borrowed from Daniel M. Haybron. Haybron uses these criteria for evaluating theories of happiness. I do not think that there is a special kind of relationship or equation that can be made between health and happiness.

[16] Haybron, 2008, pp. 47, 52-53.

However, I think that the criteria that Haybron uses are good criteria to use when evaluating theories of health because of the type of thing health is. We use health as an evaluative, practical and theoretical concept. We value health, or at least we disvalue ill-health and our theory or concept of health needs to be able to accommodate or explain this.

We use the concept of health in our daily lives and we use the concept for both practical and theoretical investigations. We are also typically pretty good at applying this concept correctly in our day-to-day lives. I think that these criteria are a good means to evaluate and tidy up theories and concepts of this kind. The goal in philosophy is not merely to passively track our everyday concepts, which are typically messy. Our everyday concept of health has grown organically for a very long time, across many different cultures and belief systems. Parts of our everyday concept of health are quite new and others are left over, taken out of context, from times when we had a limited understanding of health, our bodies, and related concepts like disease. Because of this we need to tidy up our concept of health. This requires that we get rid of some of our ordinary notions, change others and see which ones can stay just as they are.

However, to do this successfully the end product must still resemble what we think health is, so that we can continue to use the concept to do all of the things that we expect it to do. This is why using our ordinary notions as a starting point is so important. The end result of this kind of construction should not be so far removed from our ordinary notions as to be referring to something else entirely. Haybron argues that the use of folk concepts (or our ordinary notions) is important for two reasons: we care what our folk

concepts are like because we use them all the time; and we are typically right to care about them because they are usually about things that are significant to us. Haybron argues that "[b]y and large, folk concepts are the starting point of inquiry; they provide at least the initial vehicles for thinking about the things we care about." [17] Below I will explain in depth why each of these criteria is important for evaluating theories of health.

A successful theory of health must be practical in the sense that we can use it in our day-to-day life; we can use it when applying health-related concepts and making judgements about health. However, a philosophical theory of health must also be capable of doing the theoretical work we would require of it. A successful theory of health must be capable of refining or expanding our health related concepts, as well as being able to explain the relationships between different health concepts like the relationship between health and medicine.

A theory of health must accommodate our normal usage and application of our concept of health.[18] If our theory of health is so far removed from our ordinary usage or application of our concept of health, then the theory of health would be of no practical use to us. The reason that we aim to construct a theory of health is so that we can apply it with consistency to our day-to-day life and use it to classify states as being more or less healthy. Our theory of health influences what gets included in medicine and as a topic of research in the medical sciences, so a theory of health would also be used to clarify

[17] Haybron, 2008, 48.
[18] Haybron, 2008, 52.

how best to promote health and to determine what actions or treatments an individual must undergo to promote or restore healthier states.

A theory of health must be coherent and so it may not fit with all of our possibly conflicting ordinary notions of health, supposing that some of our everyday applications of our concept of health are inconsistent. Coherence indicates strength for a successful theory because it shows that the theory can be consistently applied across a large range of different cases. A theory must be capable of giving consistent answers to questions we seek to use the theory to explain. A theory which gives conflicting answers to questions would be of little practical or theoretical use.

Lastly, a successful theory of health must be able to explain why we value states of health over states of unhealth.[19] Why is health so important to us? What makes health something that we value? A successful theory of health must account for why people think that health is important. The normative aspect of a theory of health bridges the practical and theoretical uses of a theory of health.[20]

When constructing a theory of health we must first begin by taking our ordinary or folk notions of health into consideration. Below are some ordinary notions that we might start with.[21] When thinking about health one ordinary notion is that having a disease is always harmful and non-beneficial to the person that has it. We often also believe that a disease affects people

[19] Haybron, 2008, 55.
[20] Haybron, 2008, 53.
[21] The list of ordinary notions of health provided is not exhaustive, we have many ordinary notions about health. The listed notions are designed to be examples, or a guide to what our ordinary notions of health will look like.

across the world in the same way, but access to health care can change people's chances of getting treatment. However, we also think that having a natural resistance to getting certain diseases is a good thing. There are some conditions that confer natural resistance to some other disease, the condition is still harmful to the person that has them, but in some environments having the condition can be beneficial to the person who has it.

Some other ordinary notions of health could include things about one's responsibility or blameworthiness for becoming ill, and these notions may differ depending on the type of illness or health problem that is being discussed. We can have ordinary notions about the role that luck plays in one's health. These notions include some beliefs that we might have about how much control people have over their health and what types of control that they have and how their choices impact on their health. Public awareness campaigns can play a role in helping to change or shape our ordinary notions. Experience may also play a role in altering or developing ordinary notions, so that some people may have ordinary notions that would not be familiar to many other members of society. However, these differences would not be so pronounced that these individuals appear to have a completely divergent conception of health.

From this base we begin our investigation into which of these notions are significant and important to us and will get included, and which will not.[22] To construct a theory of health one must not be wedded to the ordinary notions of health; one must assume from the beginning that our ordinary notions of health will need rehabilitation. The construction of a theory of health will

[22] Haybron, 2008, 48.

pick out the important parts of our ordinary notions of health and allow for the pruning of the less important parts. Through the selection, rehabilitation, and pruning of our ordinary notions of health we will eventually construct a coherent theory, which has all of the features of a successful theory of health.

Some of our ordinary notions will prove to be false. The ordinary notions about health that we have might not prove to be as universal as we might think they are. For instance, *some* diseases do benefit people in some ways. There can be instances of *some* disease that do not cause the patient any problems, meaning that they do not experience any symptoms, so arguably they do not really harm the patient (for example, there are cases of asymptomatic cancers that develop late in life and will never cause the individual any problems). This being the case, ordinary notions that make claims that include 'always' or implies that it can be applied to all diseases equally are not as strong as we think they might be. These ordinary notions need to be altered or removed.

However, we may be able to keeps some of these ordinary notions simply by changing the strength of the claim. It is true that most, but not all diseases are harmful to the person that has them and that most diseases, but not all are non-beneficial. Making these alterations to our ordinary notions is what is meant by rehabilitation. We also need to weigh up the importance of some of our ordinary notions. Above I've mentioned ordinary notions that involve responsibility, blameworthiness, choice, and luck. The weight that we give these notions might need to be adjusted. It could be possible that luck plays a much larger role in determining a person's health than we might think, or maybe choice is restricted much more than we tend to believe it is. If our

choices are restricted by things that we have little or no control over, then this is going to change how responsible or blameworthy we are. Taking these things into consideration and evaluating our ordinary notions we can determine which of these notions needs to be included, of those some may require rehabilitation, and which notions should be discarded.

The method for constructing a theory of health that has been outlined above is not the only method. An individual may choose to prioritize one criterion over the others, or choose to only use some of these criteria. I will outline two possible methods below and explain why I think they are not as effective as using all four criteria.

In developing a theory of health an individual may seek maximum fit to our ordinary notions of health. The maximum fit method would require one to include all of our ordinary notions of health in the theory. I do not think that this would be the best approach to constructing a theory of health because it would be difficult to apply practically and theoretically. We have conflicting notions or concepts of health that vary within individuals' ordinary notions of health, across populations, and between cultures. A theory of health which is constructed with maximum fit to our ordinary notions would give conflicting results when we are attempting to apply it. For instance, a theory of maximum fit could indicate that a state or action is both unhealthy and beneficial or health promoting at the same time.

Take the genetic blood disorder sickle cell anaemia, for instance. According to our ordinary notions of health this condition would be deemed unhealthy because it can cause episodes of pain called sickle cell crisis, as well as

symptoms of anaemia such as breathlessness and tiredness.[23] At the same time there are benefits to having sickle cell anaemia such as protective effects against malaria.[24] Above I listed several ordinary notions of health that would apply to this example. These notions included things about the nature of a disease namely that they are harmful, non-beneficial and that they would be so across environments. Another ordinary notion about health indicates that something that helps to protect us from illnesses or diseases promotes our health; this is part of the reason we get vaccinations, they do not improve our health, but they do promote our health through protecting us. A theory of health with the maximum fit to our ordinary notions would say both that individuals with sickle cell anaemia are unhealthy and that having this blood disorder promotes their health or benefits them. It looks as though the very thing that makes the individual unhealthy also simultaneously promotes their health, at least it would promote the health of those individuals who live in areas where malaria is prevalent. A maximum fit theory of health gives us contradictory answers with regards to these individuals' health and leaves us unable to determine whether sickle cell anaemia should be valued or not.

A theory of health which gives us conflicting answers cannot do what we expect or want our theory of health to be able to do. It cannot give us consistent answers to questions. It would have a difficult time giving a clear explanation of what health is, and with the many conflicting ordinary notions of health that we have this theory would have difficulty explaining the

[23] NHS Sickle Cell Anaemia, Accessed on April 15th 2014. http://www.nhs.uk/conditions/Sickle-cell-anaemia/Pages/Introduction.aspx.
[24] Williams, 2005, 188.

relationship between health and health-related concepts. It would be unable to be applied consistently to identify states of health or unhealth, and it would have a difficult time giving a consistent answer to why we value health the way we do.

One might try to construct a theory of health that includes maximum fit to only those ordinary notions that are consistent. Aiming for maximum fit with consistency may appear to be an ideal way to construct a theory of health, but it can run into trouble when trying to determine which ordinary notions should be kept and which should be discarded. This process would need to include some method of determining what the salient features of the ordinary notions of health are, which makes their consistency a better fit than the other possible consistent ordinary notions of health. The third criterion, why we value health, could be helpful to those trying to construct a theory of health that fits maximally with our ordinary notions of health and that is also consistent. The process for doing this might begin by determining why we value health, or what makes in valuable, then using this they can determine which of the available consistent sets is the largest. However, they would have to choose the largest consistent set; otherwise they would not be meeting their maximal fit aim. While this process would avoid the inconsistencies encountered by the maximal fit approach it is faced with the difficult problem of attempting to determine why we value health without referring to our ordinary notions of health for assistance, since our ordinary notions of health help us to determine what about health we value or why we value health. A theory of health constructed using the method described above appears to meet the criteria for a successful theory of health better than

a maximum fit theory of health, provided this method produces a theory that is both practically and theoretically applicable. A theory of health that fits maximally with our consistent ordinary notions of health may still fail to be practically and theoretically applicable. It could end up being the case that the most consistent set of ordinary notions of health are ones that are perhaps mistaken, confused, or do not mesh with scientific evidence. In which case, the theory would not be theoretically applicable, even if by mere coincidence, it can practically track things in the world. The difficulties that these two processes encounter can be avoided if we use all four criteria to construct and evaluate our theory of health. Making sure that we address our ordinary notions as a starting point, which may need to be rehabilitated or discarded as we proceed.

I.II – Theories of Health

In philosophy of medicine there are three main types of theories of health: naturalist/biomedical theories, constructionist/normative theories, and phenomenological theories. Similar to other areas of philosophy these three different types of theories of health have different strengths and weaknesses. Naturalist/biomedical theories of health aim to be non-evaluative or value-neutral; health and disease are seen as natural real-world categories, which can be identified through the biomedical sciences.[25]

Constructionist/normative theories view health and disease to be primarily or essentially value-laden concepts.[26] On these theories disease or ill-health is something that we construct based on the value we assign to that state, or the

[25] Kingma, 2017, 49.
[26] Kingma, 2017, 54.

impact a particular state has on our ability to achieve some value.[27] Constructionist/normative theories of health build illness around the social conception of a particular condition that is evaluated as being negative and not merely a physiological phenomenon.[28] The final type of theories is phenomenological theories of health. These theories take their starting point to be the first-person lived experience of illness. This first-person starting point distinguishes phenomenological theories from the other two types of theories. One of the main charges that these theories hold against third-person theories is that they begin with a third person perspective and the lived experience of the ill individual is lost or has no place.[29]

I will be looking at five modern definitions or theories of health, raising objections for each one in turn. The first two theories I will present are two possible first responses to the question: what is health? The first being a straightforward; health is the absence of disease, illness and injury.[33] Here is an answer that can be arrived at just by saying something about what health is not. If this answer seems a little unsatisfying and/or one is seeking an answer with a little more authority, then one might seek out the World Health Organisation's (WHO) definition of health.[34] The WHO definition of health will be included in this project because it is highly influential and typically publically accepted. However, it has come under a lot of criticism and some of the objections I raise have been considered by others, but not for

[27] Murphy, 2015, online.
[28] Carel, 2008, 12.
[29] Svenaeus, 2013, 224 and Carel, 2008, 8-9.
[33] Section heading Health as Absence.
[34] Section heading Health as Well-Being.

the same reasons.[35] The WHO definition uses well-being as the value that health is to be measured by and would fall into the constructionist/normative category.[36] Following this I will discuss a naturalist account first proposed by Christopher Boorse.[37] I will then discuss another constructionist/normative theory borrowed from the social sciences. This theory uses one's ability to fulfil their social roles as a means of determining whether one is health or ill.[38] The fourth type of theory from the literature that I will present is a phenomenological theory of health as discussed by Havi Carel.[39] Finally, I will then present a theory of health that I will argue does what I find the other theories of health were not quite doing. Intuitively health involves more than just the absence of disease, illness, or injury, but articulating what the *more* is may prove to be difficult.

Several of the theories presented, including my own, argue that health involves the absence of disease, illness, injury, or infirmity, depending on which theory is being presented. For these theories to be complete they would need to also include a definition for each of the concepts that apply to that given theory. Without these definitions the theory remains incomplete and it can be difficult to apply. The biological functioning account of health and the social role theory of health provide their own definition of what disease or unhealth involves, so they would not be incomplete in this way.

One of the most common distinctions made between disease and illness is that disease is the physical ailment, while illness is the feeling of being unwell

[35] Bickenbach, 2017, 962-964.
[36] Murphy, 2015, online.
[37] Section heading Health as Biological Functioning.
[38] Section heading Health as Fulfilling Social Roles.
[39] Section heading Health as Being in the World.

or unhealthy.[40] However, one cannot use the concept of health to articulate or define the concept of illness, but then use illness to define health. There needs to be more involved in the concept than saying that one is the absence of the other. Without extra content to work with all we are saying is that illness is feeling unhealthy, and health is the absence of feeling unhealthy. This does not really tell us what either thing is or how to properly apply either concept. There needs to be more substance involved for there to be a fruitful dialogue. So, one challenge for this theory of health is how to distinguish disease and illness from each other without using the concept of health in the distinction. Furthermore, defining illness as the feeling of being unwell or unhealthy is rather narrow. It reduces illness to bodily sensations associated with feeling unwell, but leaves out a lot of the other lived experiences of being ill. I think that the best conceptualization of illness would need to be phenomenologically informed and would encompass more of the lived experience of being ill. There are more than bodily sensations involved in illness, such as, social factors and self-identity. I will go into more details about the lived experience of illness below (Section I.VII).

There is little to no work that has been done on injury. Possibly philosophers do not find injury to be a philosophically interesting topic. However, we need some theory of what an injury is for a complete theory of health if the definition of health is to be used. What is an injury? How long does it last? If an individual has permanent physical damage due to an injury are they in a perpetual state of injury, or are they no longer injured once the external damage has healed (for example, once stiches have been removed)?

[40] Law and Widdows, 2007, 308.

Providing these definitions is a large task and goes beyond the scope of this chapter. This being the case, the theory of health that I propose will remain incomplete for the time being. However, the objections raised to the theories of health presented do not rest on the lack of these definitions.

I.III – Health as Absence

The first theory of health that will be considered defines health as simply the absence of disease, illness, or injury.[41] This theory of health is not found in the philosophical literature, but might be a first attempt as answering the question: what is health? As this is a straightforward attempt as answering the question and one that might be easily arrived at I want begin the philosophical investigation here. This theory of health identifies states which reduce health and determines that health is the absence of these states. In this way, this theory defines health through what it is not.

One of the main objections to this definition of health is that when it was first proposed it moved the idea of health from incorporating mental, emotional, and physical aspects, towards a definition that focused strictly on physical ailments.[43] Since this definition of health relies so heavily on the definition of disease, illness, and injury this objection may not be appropriate. For example, if disease were defined in just physical biochemical terms then this objection would be justified. On the other hand if disease, illness, and injury were defined in such a way that one or more of them includes not just physical ailments, this objection could be avoided.

---

[41] Seedhouse, 2001, 11.
[43] Murphy, 2009, online.

The absence of disease, illness, and injury may appear to fit sufficiently with our ordinary notion of health, but I think that this definition is too narrow and can be difficult apply. This is because our ordinary notions of health include more than the absence of disease, illness, and injury. For instance, sickle cell anaemia can be seen as both beneficial and burdensome, we often consider those who can participate in their daily activities as being healthier than those who cannot. Sickle cell anaemia would insure that the individual in question would be free from contracting malaria, so they would have a guaranteed absence form this specific disease.

However, the health as absence theory would give us conflicting answers in the case of sickle cell anaemia. I do not think that a theory which focuses solely on this absence will fit sufficiently to our ordinary notions, making this type of theory unsuccessful because it does not fulfil the sufficient fit criteria. The problem for this theory is that it is too narrow to fit with our ordinary notions of health.

I.IV – Health as Well-being

More recently theories of health have attempted to accommodate the inclusion of both mental and physical health within their theory. One of the attempts to do this has been made by the World Health Organisation. According to the World Health Organisation health is defined as:

> [A] complete state of physical, mental and social well-being and not merely the absence of disease or infirmity.[45]

This definition includes more than just the absence or infirmity and does not focus only on physical ailments like the previous theory. However, this move goes too far. There can be two possible interpretations implied by the wording of this definition. The definition can be expressing an ideal which we should all aim or strive for, or it can be expressing the idea that health is something that you have or you do not. I think that the most charitable interpretation is that the definition is expressing an ideal instead of a binary relationship between health and unhealth. If the second interpretation were the intended interpretation it would mean that health could not be measured in degrees and statements about something or someone being more or less healthy cannot be accommodated by this theory.

The WHO definition of health does not meet the criteria of a successful theory of health which I have outlined above. Granted, the WHO definition of health gives us an explanation for the normative significance that we assign to health. The WHO definition of health does not sufficiently fit with our ordinary notions of health. On this account 'health' is co-extensive with 'well-being', but this is completely divergent from our ordinary notion of health. I think that health can certainly contribute to well-being but it is not the same thing as well-being. This definition is too broad as it includes too many aspects of an individual's everyday life in the definition of health.

[45]World Health Organisation s.v. "Health" Accessed February 16th 2014. http://www.who.int/about/definition/en/print.html.

Social well-being can include things like wealth, income, and education. Although some of these things can and do have an effect on individuals' health they are not what we would include in our concept of a healthy individual. There has been a lot of research that has looked at social determinants of health.[46] This research has found that things like income and education can be correlated with health states, but this does not mean that we should include these things in our definition of health.

Something can have an effect on people's health, but not be part of health itself. For instance air quality. Typically in large metropolitan areas has poorer air quality than smaller cities or rural areas. Poor air quality is linked with premature death and disease. Some health problems associated with poor air quality are "heart disease, stroke, chronic obstructive pulmonary disease, lung cancer and acute respiratory infections in children."[47] While the effect of poor air quality on health is recognised we do not include where someone lives in our definition of health. This is just one example where we recognise that something can have an impact on health, but do not include it in our definition.

I think that social determinants of health are the same. The danger of including social aspects in the definition of health is that it medicalizes social problems and then it makes them harder to address, because medical problems are typically handled by the health care system. These systems are likely to be ill-equipped to adequately address these types of social problems.

---

[46] World Health Organisation "Social Determinants of Health: Evidence" Accessed November 14th 2018 https://www.who.int/social_determinants/themes/en/
[47] World Health Organisation "Ambient air pollution: Health Impacts" Accessed November 22nd 2018 https://www.who.int/airpollution/ambient/health-impacts/en/

This type of medicalization is also problematic because those who find themselves to be lacking in social well-being are by definition unhealthy with no means of medically treating the individual. Medical treatment for these types of social issues would be inappropriate. There is no medical treatment for poverty, or not having access to good schools. Not only this, but the health care system isn't equipped or the best choice of governing body to improve the education system, provide financial support in times of need, or address unemployment.[48] It might be the case that social and economic policies have a big impact on the health of a population,[49] but these things should not be included in our definition of health.

Wealth is sometimes included in social well-being and the inclusion of this in health is problematic. The amount of wealth an individual has does not *by itself* make them more or less healthy. If all of the individual's wealth were suddenly taken away it would be unlikely that they would be bedridden or die from the loss (in the event that the individual in question was not already bedridden and close to death). It could be argued that in the long term having all one's wealth taken away would have an impact on the individual's health. However, the reduction in the individual's health is likely to be the result of many factors not just the loss of their wealth. If the individual were to still have money coming in, then they many not experience any adverse health problems. The impact that wealth has on an individual's health only goes so far. At some point on the scale between very poor and very rich an increase of capital no longer correlates with an increase in health. On the other hand, if

[48] I do acknowledge that at one time the Department of Health was responsible for affordable housing, but to my knowledge this has since changed and I think that that is probably a good thing (Stuckler and Basu, 2013, 131).
[49] Stuckler and Basu, 2013, xi.

health were suddenly taken away from an individual they would be bedridden or possibly die from the loss.

Some may argue that wealth should not be included in social well-being, but this same point can be made using education as an example. An individual's education does not directly affect their health: if an individual does not have a formal education it does not automatically make the individual unhealthy. Education is one factor which has been identified as being a social determinant of health, but many of the social determinants of health share complex relationships to one another. The lack of formal education may limit the opportunities available to an individual in other ways and so it could indirectly impact on their health, but this would have more to do with social factors than the individual's health directly. Lack of formal education reduces one's ability to find a well-paying job, which can then have an impact on whether one can afford adequate housing, buy nutritional food, afford appropriate health care, and many other things. All of which would work in combination to impact on an individual's health. Education is also distinct from things that contribute or detract from health in the sense that once an individual obtains it what they have learned generally cannot be taken away. This is so unless they suffer from some significant head trauma or develop a severe cognitive impairment. The loss of what they have learned does not result in their state of unhealth, but instead is the result of that state. This being the case it seems as though things such as wealth and education should not be included in the definition of health.

My main objection with the WHO definition of health is that it makes health and well-being appear to be co-extensive, which includes too much in the definition of health and does not fit with our ordinary notions of health.

I.V – Health as Biological Functioning

This section will look at a naturalist/biomedical theory of health proposed by Christopher Boorse. Boorse aimed to put forward a value-free theory of health. Boorse's theory of health says that health is the normal functioning of an organism, where 'normal functioning' is what allows the organism to survive and reproduce.[50] For naturalist/biomedical theories disease would be a deviation or malfunction which interferes with one or more functions that the organism typically preforms.[51] For these types of theories to be helpful they must answer several questions. How is normal functioning to be defined? Should normal functioning be defined as the species-typical biological functioning, or a statistical norm, or an idealised state for what the organism would need to be best suited to survival in their environment?[52] What does it mean for an organism to malfunction?

There have been several attempts to determine what the 'normal functioning' of an organism is. Boorse argues that normal functioning is species-typical functioning in accordance with the species' functional design. When presenting this theory of health Boorse explained species-typical function as being determined by the statistically typical biological functioning which contributes to the survival and reproduction of members of a reference

[50] Boorse, 1975, 57.
[51] Boorse, 1975, 58.
[52] Murphy, 2009, online.

class.[53] The reference class is a group of individuals of the same species who are the same age and sex. By looking at the functioning of the reference class across the species we can determine what the species-typical functioning would be for the organism to survive and reproduce. The species-typical functioning of the reference class of an organism is used to determine what the organism's functional *design* is.[54] The functional *design* of a species is a composite of comparative physiological states which have been gathered from across a population and used to determine the ideal specimen of that species. "Each detail of this composite portrait is statistically normal within the species, though the portrait may not exactly resemble any species member."[55] On this account Boorse defines health as:

> *Health* in a member of the reference class is *normal functional ability:* the readiness of each internal part to perform all its normal functions on typical occasions with at least typical efficiency.[56]

One way to define disease on this view could be as an internal state which impairs the organism's normal functional ability, causing the organism to function below typical efficiency. Alternatively, a disease could be defined as a limitation on the organism's functional ability which is caused by external or environmental agents.[57]

The attempt to define health and disease in biological terms, as has been outlined above, has several difficulties. The first difficulty that I will discuss is

---

[53] Richman, 2004, 21.
[54] Richman, 2004, 21.
[55] Boorse, 1977, 557.
[56] Boorse, 1977, 555. Boorse's emphasis.
[57] Boorse, 1977, 567.

related to the need for a theory of health to be able to explain the value that we assign to health. Boorse's aim was to produce a value-free theory of health, but this ambition is misplaced. Because of the type of thing that health is and that we do assign value to it; an attempt to produce a truly value-free account of health alienates the concept from how we use and understand it. So, in some sense, this issue relates not just to the value criterion, but also the ordinary notions criterion.

Speaking strictly in biological terms the values that we assign to different health states cannot be explained. Instead any value judgements that we attempt to make concerning different health states come from outside of having that particular health state: they are added on afterwards. Boorse attempted to address this difficulty by making the distinction between disease and illness, arguing that illnesses are a subclass of diseases that have certain normative features.[58] For Boorse an individual has an illness when they have a disease that is serious enough that it somewhat incapacitates the bearer. This incapacitation is what supports our normative judgments about illness.[59] However, I don't think that this distinction helps him to overcome the difficulty. I think that Boorse would be hard pressed to find an adequate group of diseases that do not have normative features incorporated into how we conceive of them for his distinction between illness and disease to be effective. There are also instances where patients have an illness which would be sufficiently incapacitating, but they do not appear to have any effect on the individual's internal system's functional abilities. Conditions such as seasonal affective disorder do not impair the individual's internal systems from

[58] Richman, 2004, 21.
[59] Boorse, 1977, 552.

functioning within typical efficiency, but they can certainly induce incapacitating feelings in the bearer of the disorder.[60]

One objection to Boorse's theory is that it isn't value-free at all. Value sneaks in through the choice of goals (survival and reproduction) species typical biological functioning is meant to contribute to.[61] However, even if Boorse's theory is not value-free we might think that the value latches onto the wrong things. This is where the value issue links up with the ordinary notions criterion. Boorse's theory relies on the definition of normal functioning leading to the survival and reproduction of the organism. The hallmark of health is not only that the internal systems of the organism are functioning, but that this functioning contributes to the organism's ability to survive and reproduce. While survival and reproduction are important and people generally think that their body functioning properly contributes to health, but the goals of survival and reproduction are not generally central to people's concept of health.[62] One might argue that survival is a presupposition to our health related notions, but we tend to think of health in a way that goes beyond survival. These things that are beyond survival are the types of things that we typically hold central to our ordinary notions of health. Body functioning comes to mind when people are thinking about how the body's functioning impacts on the things that they do (engaging in daily activities,

---

[60] NHS Seasonal Affective Disorder, Accessed on April 16th 2014. http://www.nhs.uk/conditions/seasonal-affective-disorder/Pages/Introduction.aspx.

[61] Kingma,2017, 53.

[62] There is a group of people who at some point in their life would regard an inability to reproduce a health issue, so the goal of reproduction could become central to some people. I am unsure to what extent these individuals would incorporate this goal into their view on health. However, I think for a large portion of the population reproduction would not play a central role in their conception of health.

achieving set goals, etc.) and how they feel (whether they are in pain, have difficulty breathing, etc.).

Boorse's theory relies heavily on the reference class that is used to determine what the species-typical biological functioning is, which is then used to determine the boundaries between health and disease. For Boorse a reference class is "a group of organism of the same species, sex and age."[63] However, this is not particularly fine grained[64] and does not fit with our ordinary notions. There are other things that should be considered when thinking about whether people fall into the range that is considered healthy. What might be unhealthy for one group of people could be within a healthy range for another group. For instance, a typical resting heart rate for an average adult is between 100 and 60 beats per minute (BPM). This is considered a healthy range to be in. Dropping below 60 BPM can be an indicator of bradycardia, which can lead to other health concerns like poor circulation (to you brain and other areas) and fainting.[65] However, athletes that engage in a lot of extra training typically have lower resting heart rates than the rest of us; between 60 and 40 BPM.[66] These rates are low enough to be considered unhealthy and a cause for concern for most adults, but are considered to be healthy for highly trained athletes. The reference class that we use to determine the range of normal or healthy needs to be able to take things like this into account, so sex and age are not the only features that should be considered.

---

[63] Cooper, 2002, 266.
[64] Cooper, 2002, 266.
[65] Roland, accessed November 27th 2018
https://universityhealthnews.com/daily/heart-health/low-heart-rate-dangerous/
[66] MacGill, accessed November 27th 2018
https://www.medicalnewstoday.com/articles/235710.php

Making the reference class more fine grained can run into further difficulties because once the reference class becomes small enough it can make Boorse's account of functions problematic.[67] For Boorse, functions of a system or sub-system are determined by a statistical survey of the reference class.[68] When a system or sub-system is functioning properly they contribute to the organisms ability to fulfil their goals, in this case the goals in question are survival and reproduction. The account of functioning employed by Boorse can rule out accidental instances as counting as a function of the system or sub-system because the reference class is so large. The example that Rachel Cooper uses is that both sweating and dumping water on oneself cool down the body, but only sweating has this function on Boorse's account.[69] This is only possible because the instances of individuals accidentally (or possibly purposely) dumping water on themselves when they are hot would be rather rare in a reference class that is determined by age, sex, and species. Accidental instances would be infrequent and many of them would not be things that individuals typically do. Once the reference classes become finer grained, and inevitably smaller, these types of accidental contributions to the goals of a system or sub-system will become more prevalent, leading to them being included as functions. This is a good objection to Boorse. So far I've said that using too few features to identify a reference class is counter to our ordinary notions and the reference class needs to be finer grained to fit with our ordinary notions of health. However, this objection points out that if the reference class is too fine grained we will again find a poor fit with our ordinary notions about health.

[67] Cooper, 2002, 266.
[68] Cooper, 2002, 265.
[69] Cooper, 2002, 266.

The final ordinary notions issues that I will raise is that Boorse's account allows for the possibility that there may be no healthy member of a species. It is not often that we would ordinarily agree that every member of a population is diseased. There are definitely times when we would be willing to identify an entire subset of a population as diseased, but those times are most often instances where there are environmental factors which appear to be causing disease. A theory which rigidly indicates that every individual is not healthy does not fit with our ordinary usage or application of the concept of health. For any individual to be considered healthy, on Boorse's theory, *all* of their internal systems must be functioning with at least typical efficiency. The full functioning of every internal system is not generally how our ordinary notions of health are applied to describe ourselves or others. Taking these four issues into consideration I would argue that Boorse's theory has departed too far from our ordinary notions of disease and health and fails to address the value criterion to be a successful theory of health.

The section focused mainly on Boorse's theory of health. However, the issues regarding meeting the criteria for a successful theory of health would be similar for other naturalist theories. A strictly biological value-free theory of health and disease would have difficulty with the both the value and ordinary notions criteria for a successful theory of health. While our ordinary notions of health do involve some reliance on biology and the medical sciences; there are aspects of health that go beyond the science and a successful theory of health needs to accommodate this.

I.VI – Health as Fulfilling Social Roles

The fourth theory of health that will be considered in this chapter is a theory that argues that health is being able to fulfil one's social roles. Thus, anything preventing you from fulfilling your social roles is unhealthy or a disease.[70] Social roles include tasks, activities, and roles that the individual is expected to perform according to the norms of their society. This theory is an example of a constructionist/normative theory of health. Under these types of theories disease is defined entirely by the culture or society that the individual lives in. These types of theories build a theory of health around a value or set of things they view as valuable,[71] in this case the value that is used is fulfilling one's social roles.

This theory defines disease too broadly in claiming that anything preventing an individual from fulfilling their social role is either a disease or an illness.[72] This definition of disease does not fit with our ordinary notion of what a disease is. On this account things such as poor education or poverty would be considered a disease if or when they prevent the individual from fulfilling their social roles. It would also be the case that any wilful deviation from the expected social roles would also be considered a disease. This theory can give an account as to how something can be seen as a disease at one point in time and not at another: this change is the result of society reclassifying something from being a disease to not being a disease. However, a social definition of disease cannot give an adequate account of the claim that the previous classification of something as a disease was mistaken. An example of this is

[70] Seedhouse 2002, 44.
[71] Murphy, 2015, online.
[72] Seedhouse 2002, 45.

drapetomania: in 1843, Samuel Cartwright argued that American slaves who attempt to run away or escape were afflicted with the disease drapetomania.[73] With the abolishment of slavery there was no longer a cause for a slave to run away, so this disease appears to no longer exist within society. The classification of drapetomania as a disease seems to be mistaken; many would argue that this disease never existed no matter what the society at the time thought. A social definition of disease cannot explain how this mistake can be possible. It would indeed imply that the disease did in fact exist at that time. This is an issue with constructionist/normative theories of health more generally and not just this theory of health.[74]

Another way that the social roles theory does not fit with our ordinary notion of disease is that it defines disease in a way such that any deviation from what is considered to be the appropriate social role for that individual would be seen as unhealthy. If an individual refuses to participate in the roles that they have been socialised to take part in then this refusal would be preventing them from participating in their social role and by extension the refusal would be seen as a disease on this account. There are far too many cases through history which contributed to changes in society which on this theory of health would all be considered to be the result of unhealthy or diseased individuals affecting society. Those who participated in the abolishment of slavery, feminist movements, human rights movements, revolutions, and hermits are a few examples of people who refused to fulfil

[73] Murphy, 2009, online.
[74] Murphy, 2015, online.

their social roles within the societies that they resided in.[75] An account of health that would label individuals who are attempting to change society or get their society to see the unfairness of its current policies or practices, as being unhealthy or diseased, does not seem to be doing what we want or need a theory of health to do.

The social roles theory of health does not give us any explanation as to why we should care about social roles in the first place. Since health and disease are tied so tightly to social roles this theory would have to give us some account as to why we should care about social roles, or why they are so important. Without this explanation we have no way of justifying the normative significance that we assign to health. The examples of changes in social roles that I have given show that some social roles are not or possibly should not be valued. How are these social roles meant to give an account or explanation of the normative significance that we place on health? The social roles themselves appear to lack the explanatory power that they would require for them to fulfil the normative significance criterion for a successful theory of health.

I.VII – Health as Being in the World

Phenomenological theories of health start from the first-person lived experience of health and illness. The lived experience of an individual includes physical, psychological, and social aspects.[76] These can all be

[75] This is not a statement about the merit of these changes—the changes could have been beneficial or detrimental to the society that they happened within—but the point is that whether the change in the society was for better or worse the individuals who were not fulfilling their social roles would be deemed diseased or unhealthy on this view.
[76] Carel, 2008, 12.

changed by ill-health and a theory of health that does not accommodate or include this will be missing something important. Many of these theories arrive at a theory of health from the opposite starting point than the theories presented so far. When looking into these types of theories you will often find phenomenological accounts of disease or illness, so to reach a picture of what health is you need to work backwards. However, these theories do more than say that 'this is our picture of illness and health is what isn't included here'. To describe the theories like this would be to do an injustice to them. The theories are not a negative account of what health is, and by negative I mean that they define health by what it is not. Fredrik Svenaeus argues that health is experienced as a homelike being-in-the-world which is contrasted with the unhomelike being-in-the-world that one experiences in illness.[77] Svenaeus says:

> To be ill means to not be at home in one's being-in-the-world, to find oneself in a pattern of disorientation, resistance, helplessness, and perhaps even despair, instead of in the homelike transparency of healthy life.[78]

It is the transparency of the body in our daily lives that motivates these phenomenological theories to focus on the lived experience of illness or disease instead of focusing on health. Both Fredrik Svenaeus and Havi Carel argue that a phenomenological account of illness are *compatible and can even complement* a naturalist theory. [79] When Carel begins outlining the phenomenological account of illness, in *Illness,* she makes the distinction

[77] Svenaeus, 2013, 232.
[78] Svenaeus, 2013, 232.
[79] Svenaeus, 2013, 237 and Carel, 2008, 11.

between the material or biological body and the first-person experience of that material body.[80] This is important because in illness these two bodies come apart. In health the body is transparent and taken for granted, little thought is given to it, but in illness this oneness can become an otherness.[81] The material body is drawn out of the background and becomes the focus of our attention and the difference between the two bodies become noticeable. It is because of this separation of the two bodies that she says:

> We can now begin to see how being ill is not just an objective constraint imposed on a biological body part, but a systematic shift in the way the body experiences, reacts and performs tasks as a whole. The change in illness is not local but global, not external but strikes at the heart of subjectivity.[82]

Carel's account of illness covers not just the bodily aspects of illness, but also many of the social aspects of illness. In illness the individual can begin to see the body as other, limiting, and betraying the self.[83] Illness can alter how one interacts with other people, not just healthcare professionals when the individual is occupying the role of patient,[84] but how illness can colour the interactions with other people in all sorts of social engagements. [85]

These first-person experiences are something that fall out of other types of theories of health and because they fall out of those theories they are often ignored or remain unaddressed in the professional setting. Some of these

---

[80] Carel, 2008,26.
[81] Carel, 2008, 26.
[82] Carel, 2008, 29.
[83] Carel, 2008, 34-37.
[84] Carel, 2008, 39-41.
[85] Carel, 2008, 50-60.

social aspects make their way into our ordinary notions about health, but when they do the notions are muddy and a bit confused or unformed. We acknowledge that there is a social aspect to health, but think of it more in terms of physical or psychological limitations on the ill person's part. However, the fact that interpersonal interactions require at least two participants to take part and both can suffer from limitations because one of them is ill, does not often occur to most people. This isn't saying that, because our ordinary notions imply that the limitation is one sided, we should say that for this reason alone the phenomenological account presented fails on the ordinary notions criterion. I think that this example gives use reason to think about altering our ordinary notions to include this. However, I think that *on its own* a phenomenological account of health and illness does not meet with our more central ordinary notions, the ordinary notions that would be resistant to pruning or revision. Of the phenomenological accounts presented here, neither has insisted that it is or should be a standalone theory, so some of these central notions may still be accommodated if it were combined with another theory.

I.VIII – The Combination Theory of Health

I think that we need a theory of health that does not focus solely on the absence of disease, illness, or injury because I think that we use the concept of health much more broadly than this. Although the absence of disease, illness, and injury are intricately entwined in our ordinary notion of health, there seems to be more involved in the ordinary notion of health than this absence; it seems to me that a theory of health involves a combination of this absence with *something else*. I would argue that for a successful theory of health to be

constructed one of the important parts of our ordinary notion of health which we would need to include is this absence, but the role of the absence of disease, illness, and injury would only be a part of the theory of health. The absence of disease, illness, and injury must be accompanied by *something else* in order to fully accommodate our ordinary notions and application of our concept of health.

For example, there appears to be an important difference between an individual, Sally, who has a disease or illness and is still actively participating in many areas of her day-to-day life and an individual, Lizzy, who has a disease or illness and is bedridden or hospitalised. This distinction may appear to be obvious as Sally seems to be clearly healthier than Lizzy, but if our theory of health only takes into consideration the absence of disease, illness or injury then our theory of health will have a hard time indicating why there is such a difference between these two individuals, especially if they both have the same disease or illness.

What exactly is it that makes Sally healthier than Lizzy? To answer this question one might think that Sally was healthier because she was able to fulfil her goals or aims through her continued participation in her day-to-day life. Determining to what degree an individual is healthy would include both the absence of disease, illness, and injury and being able to fulfil one's goals and aims, so an injury could affect an individual's health more or less depending on their ability to fulfil goals or aims. Not all or any goals or aims should be used to determine whether the individual is healthy, however. It seems like not all goals or aims are of the right sort to count towards an individual's health. In fact, an attempt to define health with regards to the

fulfilment of goals and aims and the absence of disease, illness, and injury is problematic from the start for two distinct reasons.

First, for this type of definition to work one would need a way to distinguish the goals or aims that count towards the definition of health. Surely the achievement of all or any of the individual's goals and aims doesn't contribute to whether the individual is healthy or not. If this were the case we would be unable to identify some kind of standard or a way of measuring health from outside each individual. Moreover, we would not want an individual's health to be determined by how ambitious the goal-maker's goals are. For instance, consider the following two individuals. Tom is a very ambitious individual, who sets very high goals which he is unlikely to fulfil (for example climbing Mount Everest). Meanwhile, Steve is unambitious and sets very low goals which he easily fulfils (for example simply being able to make enough money with minimal effort so that he can watch television in the evenings). We would not want to say that Steve is healthier than Tom simply because Tom's goals are too high and Steve's goals are easier to achieve. Thus, limiting the types of goals or aims to be included in our theory of health to more general goals or aims is important.

Attempting to define health using goals and aims is problematic for a second reason. If the salient feature of this theory of health is its reference to general or universal goals and aims, then once someone has managed to figure out what these universal goals or aims might be one would then need a way to explain how not sharing in these goals or aims would not automatically mean that the individual is less healthy. For instance, imagine that perhaps a general goal or aim says something about having children, but some people

do not want to reproduce. A theory of health that attempts to use general goals and aims to measure health would need to have a way to explain how those individuals who do not want to have children would still be healthy.

This account of health would also need to be able to accommodate cases involving individuals who share in these universal goals or aims, but due to external forces are unable to fulfil them. For example, suppose that an individual is incarcerated for a crime and thus cannot fulfil some of these general goals or aims. The incarcerated individual should not be considered less healthy simply because they are detained. This is not to say that individuals who are incarcerated may be less healthy for other reasons, but the important feature we are looking at here is the *something else* as described by fulfilling general goals or aims. We would not say that these individuals are less healthy simply because their ability to fulfil general goals and aims are frustrated or restricted because they are detained.

This first attempt at defining the *something else* is unsuccessful. One could determine that the difficulty this type of theory of health is encountering is due to the terms 'goal' and 'aim' which were not expressing what one might have been attempting to describe as the *something else* which health should include. Another possibility is that the focus of this first attempt was placed in the wrong spot: maybe the focus should not be on the general goals or aims themselves, but instead on the individual's ability or capacity to fulfil the general goals or aims that they may have. The focus should be on what allows us to fulfil these general goals or aims—namely, people's capabilities. The capabilities that one should include in health appear to correspond to

several of the capabilities and limits which Martha Nussbaum gives when she outlines her "thick vague theory of the good".[86]

The capabilities approach, which Nussbaum and others have developed, originated in the fields of economics and development, and is used to measure quality of life.[87] Nussbaum proposes that the list of functional human capabilities that she outlines is international and not a projection from any particular culture or based on any one set of customs.[88] Nussbaum argues that capabilities are part of humanness,[89] they are items or aspects of human life that make that life distinctly human without which we could hardly identify the life as a human life.[90] Nussbaum argues that capabilities to function are such that without that item or capability a life would be so lacking and impoverished that it would not be human at all.[91] When discussing capabilities Nussbaum is presenting arguments about what makes for a *good* human life. While this is part of the motivation that Nussbaum has for creating the list of capabilities that she has, I will not be making any claims regarding what makes for a *good* human life. I think that several of the capabilities that are present on Nussbaum's list are the types of capabilities that are part of the health of the individual and should be included in a theory of health. These capabilities adequately describe the *something else* that the absence theory of health was missing. Nussbaum's list of basic human functional capabilities is quoted bellow:

---

[86] Nussbaum, 1992, 216-222.
[87] Law and Widdows, 2008, 308.
[88] Nussbaum, 1992, 216.
[89] Nussbaum, 1992, 220.
[90] Nussbaum, 1992, 216.
[91] Nussbaum, 1992, 220.

1. Being able to live to the end of a complete human life, as far as possible; not dying prematurely, or before one's life is so reduced as to not be worth living.
2. Being able to have good health; to be adequately nourished; to have adequate shelter; having opportunities for sexual satisfaction; being able to move from place to place.
3. Being about to avoid unnecessary and nonbeneficial pain and to have pleasurable experiences.
4. Being able to use the five senses; being able to imagine, to think and to reason.
5. Being able to have attachments to things and persons outside ourselves; to love those who love and care for us, to grieve their absence, in general, to love grieve, to feel longing and gratitude.
6. Being able to form a conception of the good and engage in critical reflection about the planning of one's own life.
7. Being able to live for and with others, to recognize and show concern for other human beings, to engage in various forms of familial and social interaction.
8. Being able to live with concern for and in relation with animals, plants, and the world of nature.
9. Being able to laugh, play, to enjoy recreational activities.

10. Being able to live one's life and nobody else's; being able to live one's own life in one's very own surroundings and context.[92]

The list outlined here was constructed to support Nussbaum's later arguments regarding public policy. Some of the capabilities mentioned on Nussbaum's list are clearly related to health and intertwined with what health is, or at least what would impede health if we didn't possess them. Nussbaum is giving an account of flourishing, there is more to flourishing than health, so I've only included the capabilities related to health in the combination theory of health outlined below. I will argue that the selected capabilities work in combination with the absence of disease, illness, and injury to give an account of what health is. So, the capabilities that will be included in the combination theory of health will be part of health. For an individual to be ideally healthy they would have the capabilities that will be discussed below and be free from disease, illness, and injury.[93] Health wouldn't be a capability in itself because it is made up of a combination of different capabilities and the absence of disease, illness, and injury. It also would not be a precondition for possessing and exercising capabilities, at

[92] Nussbaum, 1992, 222.

[93] The list of capabilities cited in this thesis is direct from the source. It has been brought to my attention that on a different version of the list of capabilities to function that Nussbaum argues for she includes health as a distinct capability. Health was not included as a capability in the source that I used, but if it were included that capability would be left of the list of capabilities included in the combination theory of health. This is because it would make the theory less helpful, since the theory is supposed to help us to answer the question what is health; including health in the definition is not particularly informative especially because there are several other capabilities and the absence of disease, illness, and injury included in the answer. If we say that health is the absence of disease, illness, and injury and the combination of these specific capabilities, one of which is health, we are basically saying that health is health and this bunch of other things, which then implies that health is more than health.

least the capabilities included in health, because being fully or more healthy would include having or possessing the capabilities that will be discussed below. This does leave open that health can have an impact on or possibly be a precondition to possessing and exercising other non-health capabilities.

I argue that health is something that is measured in degrees, so people can be more or less healthy, which differs slightly from how we sometimes speak of health. We tend to be quick to label people as unhealthy even when their health state isn't such that it severely impedes the individual's participation in life. I don't think that we really think of health in these kinds of dichotomous ways, as people either being healthy or unhealthy, but that we use language in this way. We use labels like healthy and unhealthy and also recognise that somethings are unhealthier than others. Because we recognise these distinctions I think that this is evidence that the way we use language is different from how we think of health.

The capabilities on Nussbaum's list which I have included are those that are internal to the individual, meaning that they are not dependant on external factors,[94] and would most likely contribute to the achievement of general goals or aims which were the focus of the first attempt of articulating what the *something else* is. Those capabilities which would be included are: mobility "being able to move from place to place"[95]; "being able to avoid unnecessary

[94] For instance, as you will notice nutrition and shelter have not been included on my list. They are both important for health and bodily functioning, but acquiring them is dependent on external factors. It is clearly the case that external factors can impact on the health of an individual, as external factors are often the cause of disease, illness, and injuries, but it is not the case that these external aspects should be included in health in their own right. It is not the virus itself that takes away from health, but the infection or disease that it causes.

[95] Nussbaum, 1992, 222. This capability as listed here refers to the individual's ability to do so on their own and is therefore meant to be internal to the individual.

or nonbeneficial pain and to have pleasurable experiences"[97]; "[b]eing able to live out to the end of a complete human life, as far as possible; not dying prematurely, or before one's life is so reduced as to not be worth living"[98]; having the ability to form future looking plans and desires; and having the ability to laugh[99] and form social bonds or attachments if one chooses to do so.[100] This list of capabilities falls in line with what one might have in mind when attempting to use general goals or aims to explain the *something else* that is needed in a theory of health.

I think that health consists in the presence of these capabilities and the absence of disease, illness, and injury.[101] The combination of each of these capabilities and the absence of disease, illness, and injury will be used to determine to what degree an individual is more or less healthy. This combination of features fits well with our ordinary notions of health, allowing us to explain the application of our concepts of health when we make distinctions between individuals' level of health. An ideal state of health would be the complete absence of disease, illness and injury and all of these different capabilities being present in the person, while a state of complete unhealth would be lacking most or all of these capabilities and having some debilitating disease, illness, and/or injury. For this to be a

---

However, if someone lacks the ability to do this on their own then there are medical interventions or products designed to assist them.

[97] Nussbaum, 1992, 222.

[98] Nussbaum, 1992, 222.

[99] Nussbaum, 1992, 222.

[100] When I refer to having the ability to form social bonds and attachments I am referring to the ability to communicate in some way and develop the appropriate affective attitudes. This does not refer to the need for other people to engage with or actually form any such attachments.

[101] This theory would require an adequate account of disease, illness, and injury before it could be applied. In this sense it faces a similar challenge as the Health as Absence theory presented above. This challenge could be remedied once a satisfactory theory of disease, illness, and injury is present.

complete theory of health I would need to provide an account of disease, illness, and injury. This task would be exceed the scope of this chapter and is a project on its own, but I will posit some preliminary thoughts about what this might entail. I think that an account of disease is likely to be some type of naturalistic account because whether valued or not I think that the biology of diseases are present and can fairly consistent across different cultures and species. I do not think that disease is anthropocentric as some might suggest.[102] I do not think that it is a misuse of language to refer to plants and nonhuman animals as being diseased.

I think that an account of illness will be a phenomenological one and this would then capture what is unique to human experience of ill-health. I also think that the inclusion of a phenomenological account of illness into a complete theory of health would be useful for picking out the parts of being unwell that our current healthcare system doesn't really account for, or can't really accommodate.

Earlier in the chapter I argued that our theory of health helps to shape what gets included in medicine and the types of treatments and procedures get included. Phenomenologists argue that the first person perspective is missing in medicine and theories of health/illness and I think that this is true. Above I mentioned that there has not been much philosophical work done concerning injury, this being the case, I currently do not have a clear idea of what an account of injury would really look like. There are certainly some perplexing questions surrounding injury, but since the main focus of this thesis is cancer

[102] Rachel Cooper makes this claim in the "Disease" and I have come across others who make similar claims.

care there has been little time to dedicate to these questions. The task would then be to make sure that these different accounts of the parts that make-up health can continue to give consistent answers to our health related questions.

This theory of health allows us to identify areas in an individual's life that make them less healthy and we can also use it to refer to the varying ways an individual can be more or less healthy. We value having the capability to function in the ways listed above, and so by including these capabilities in our theory of health we have given the theory of health the explanatory power to justify the normative significance that we attribute to health. This theory of health can also give us consistent answers when we apply it to different cases. A theory of health which includes the combination of capabilities and the absence of disease, illness, and injury has all of the features needed for it to be a successful theory of health.

Let us return to the example that was mentioned above with the two individuals with a disease. Sally has a disease, but she still engages in her day-to-day activities, she carries on with her personal relationships, and she continues to actively participate in her life. Perhaps Sally has a higher pain tolerance, or maybe she is determined to continue to actively engage in her daily activities. Lizzy has the same disease as Sally, but Lizzy is bedridden and cannot engage in any of her daily activities. This combination theory of health can tell us why Sally is healthier than Lizzy even though they both have the same disease. Lizzy appears to be lacking some number of the capabilities which Sally still has. For instance, Sally is still able to move about and complete her daily tasks, her life is still moving along relative to at least some of her life plans, and she is still engaging in her social relationships.

The combination theory of health can do much better than other theories just by being able to explain why Sally is healthier than Lizzy. The theory of health that focuses solely on the absence of disease, illness, and injury will be unable to distinguish between the different levels of health that we would assign Sally and Lizzy in this example. The WHO definition of health would be able to identify some of the aspects that make Sally healthier than Lizzy, as it would seem that Sally's level of well-being is likely to be higher than that of Lizzy. According to the social role theory of health, Sally, who continues engaging in her social roles, would be deemed healthy, while Lizzy would not. This theory fails to identify that Sally is indeed unhealthy to some degree. On the biological functioning account of health, both Sally and Lizzy suffer from the same condition, so they would both be 'diseased'.[103] However, Sally appears to be surviving and continuing to function to some degree, so it is unclear how this theory would address Sally's level of health.[104] Sally and Lizzy appear to be experiencing very different lived experiences of illness in this example, so a phenomenological account would be able to accommodate these differences.

Let us add another individual to this example. Tammy has the same disease as Sally and Lizzy, but unlike Lizzy she is not bedridden; she can still do all of the same things as Sally. However, unlike Sally, Tammy chooses to remain in bed all day. The combination theory of health would indicate that Tammy is still healthier than Lizzy because she has the capabilities that would allow

[103] I have used 'diseased' in this instance to remain true to the terminology that Boorse uses to refer to an individual who is unhealthy.
[104] This example does not speak to whether the condition would reduce the individual's ability to reproduce, and as such the example can only speak to the individual's ability to survive. The dysfunction or reduced ability to function in Sally's case does not appear to alter her ability to continue to survive.

her to continue to actively participate in her day-to-day life even if she chooses not to. It is not the fact that Lizzy remains in bed that makes her less healthy than Sally, as the case of Tammy shows, it is that Lizzy is lacking the capabilities required to do otherwise that makes her less healthy. This example shows that the combination theory of health can give consistent answers when it is confronted with different types of situations or scenarios.

The combination theory of health presented in this chapter can deal with this alteration, but do the other theories of health give us the same results in this new example? In this modified example the absence of disease, illness, and injury would give the same result as it did in the original example. It can be difficult to determine whether the WHO definition of health would give us a different answer with regards to Tammy. In some sense it would appear that Tammy's level of well-being would be higher than Lizzy's, but with regards to Tammy's social well-being, and possibly her mental well-being, it is hard to be clear as to whether her staying in bed even though her condition doesn't require it would result in a reduction. The biological functioning account would give us the same results as in the previous example. On this account Sally may still pose some difficulty, but it would be likely to class Lizzy and Tammy as being similar. Placing Lizzy and Tammy into the same category is also the answer that the social roles account of health would have. Even though Tammy retains the ability to participate in her social roles, she doesn't, and so on this account Tammy would also be unhealthy or diseased. It would be hard to determine how a phenomenological account would accommodate Tammy in this example.The answers that these different theories of health provide regarding this modified example pose similar

deficiencies as they do in the original example—thereby demonstrating that the combination theory can do a better job of distinguishing the difference in the levels of health that we would assign these three individuals.

I have argued that the combination theory does a better job of supporting our ordinary notions about the health of individuals with the same hypothetical condition. However, this is only an imagined condition and judgements that could be made between individuals. One might ask whether the combination theory does a better job at answering questions about an individual's level of health regarding real conditions. The next example will compare how these different theories of health address two different types of cancer.

Let us consider two individuals, Alice and Betty. Both of these individuals go in for a routine mammogram and receive a positive test result. However, these two individuals have different types of cancer. Alice's cancer is asymptomatic: the cancer is slow growing and will never cause symptoms in Alice's life time.[105] Betty's cancer, on the other hand, is symptomatic and grows at a much quicker pace and causes symptoms that will affect Betty's health and life.[106] Both of these individuals have a disease, so on an account of health which includes the absence of disease they will both be unhealthy to a degree, but we might be inclined to say that Alice has a higher level of health

[105] Plutynski, 2012, 311.

[106] This example is hypothetical to some degree as our current screening methods cannot distinguish between cancers that are slow growing and will remain asymptomatic, and those that will grow and cause problems for the patient. It has been noted that follow up assessments can help to determine whether a cancer is slow growing and that some woman will choose not to be treated. This is true, but there are still concerns for overtreatment that have been highlighted in the literature. This being the case, both individuals in this example would ultimately receive treatment for their condition and would be faced with the limitations and possible side-effects that treatments involve. However, if or when we eventually develop a screening method that can reduce the over treatment of these kinds of cancer, this example will cease to be hypothetical.

than Betty. If the absence of disease is all we have to go on then this may be difficult. However, the absence of disease, illness, or injury theory may be able to accommodate this intuition through illness. It might be that Betty can be deemed less healthy because her symptoms make her feel unwell.

On the other hand, the WHO definition of health can accommodate this disparity through the reduction in Betty's well-being. This method of accommodating the disparity between Alice and Betty's health may be deemed unsatisfactory because the reason that Betty is seen to be less healthy is not the right reason. Cancer and the treatment for cancer can be very limiting in different ways and being diagnosed with a serious illness can hinder someone's mental well-being. It would be the reduction in physical, mental, and social well-being that Betty would experience through diagnosis and treatment that would make her less healthy. However, Alice may also suffer from a reduction in her mental well-being from the diagnosis as well, so this would need to be taken into consideration. This theory tracks the disparity between both individuals, but it focuses on the wrong features.

On the biological functioning account they would both be deemed unhealthy. Any disparity between their levels of health would need to be accommodated through some other biological dysfunction caused by the symptoms in Betty's case. This too seems to put the emphasis in the wrong place. On this account the only means of differentiating between the level of health of Alice and Betty is the degree of biological dysfunction they both experience. Some of the symptoms experienced by individuals with cancer do not cause further biological dysfunction. On this account if the symptoms do not cause further biological dysfunction, then there is no difference between Alice and Betty's

levels of health. This being the case, the theory cannot explain why we would assign these two individuals different levels of health.

The social roles account of health would deem Betty to be unhealthy in so far as Betty's disease and treatment reduce her ability to fulfil her social roles. Alice, whose cancer is asymptomatic, would experience very little or no impact on her ability to continue to fulfil her social roles. On this account that would make her healthy. However, this theory seems to be missing the point, since Alice does have a disease even if it may not impact on her life much at all.

A phenomenological theory would likely deem Betty as less healthy than Alice because Betty's illness would have a larger impact on her lived experience. She would likely experience more of the social dimensions of illness and the lack of transparency of the body typical of these accounts. She is also more likely to experience the disharmony between self and body that is often addressed by these theories. Alice may still experience some of these changes in her lived experience as well, but probably to a lesser degree than Betty.

The combination theory of health can explain the difference between Alice and Betty's health. Both Alice and Betty have cancer, so in one sense they are both unhealthy to a degree. A theory of health should be able to explain why Alice is unhealthy in some way, but also why she might be healthier than others with a similar or the same disease. However, Betty's symptoms and treatment will likely reduce some of her capabilities. It is this reduction in capabilities that can explain why we would generally think that Betty is less

healthy than Alice. This theory also identifies the difference in these two individuals' level of health for the right reasons. The difference between the two is explained not through the possible impact on their well-being: or because the experience of the symptoms may be classed as an illness: or because the symptoms cause some other form of biological dysfunction: or because they can no longer fulfil their social roles: or differences in their lived experiences. The combination theory of health can explain the difference in these two individuals' level of health through the reduction of capabilities and the impact that this reduction has on their life.

A theory of health which includes a combination of these different capabilities and the absence of disease, illness, and injury can accommodate health promotion activities as well as preventative actions into our concept of health. For example, a theory like this one can make sense of incorporating things like healthy lifestyle changes and vaccinations into one's health promotion regimen. Medicine and medical science study the causes and cures for disease, illness and injuries, but often look to address different aspects related to health (e.g. vaccinations, nutrition guides, etc.) in research and practice. Our theory of health shapes what gets included in medicine and the treatment that we offer to patients. A theory of health which incorporates these different features into the concept of health makes the relationship between health and medicine more apparent.

II – The Relationship Between Health and Medicine

Health and medicine are two concepts that often have close connections made between them. Determining what we mean by health is important when we

are trying to determine what role medicine plays or ought to play in health, and what role medicine plays in our day-to-day life. Is the focus of medicine simply to restore health for the unhealthy individual, or does it include health promotion and preventative measures? I will address both parts of this question separately.

First, if the focus of medicine is simply to restore the individual's health, then this is going to have all sorts of implications for what can be included in medicine. A restorative focus will be constantly looking backwards, waiting for a problem to arise and then trying to address it once it is present. Working from the onset of the problem limits what can be done for the individual.

If the focus of medicine is purely restorative, then a further question is to what level of health medics should aim to restore the individual. Is the goal to restore them to the level of health that they had before the problem arose, or to restore their health to a minimum level, or possibly to 'restore' their health to a higher level than they had before the problem arose? These three possible goals have varying degrees of demandingness and would have very different measures for success. Many medical treatments can be more or less effective and this is communicated to the patients prior to treatment, but the following is a discussion about the goal of restoring patient health and how that might be deemed successful.

The goal of restoring the individual to the level of health that they had before the problem was present can be rather difficult or impossible to achieve, depending on what the problem is. If full restoration of the patient's health is the aim, then it would look like medics are rarely successful at achieving their

treatment goals and this goal would be too demanding. For example, if an individual were to present with a disease and through treatment the patient recovers from the disease, but will forever have a weaker immune system than they had before getting the disease, then the medical intervention would have failed since it could not restore the individual to the same level of health they were at before the disease presented. It could be that the hope is to restore the patient to their previous level of health, but that the actual aim is more modest than that. More plausibly the medic's goal should be to restore the individual as close to their previous level of health as possible, but it remains unclear how close to the previous level of health the patient would have to be in order for their restoration to be a success.

What about cases in which the patient had a very poor state of health before they contracted a disease: to what level of health must they be restored? How far back should their previous level of health be measured from: immediately before the patient contracted a disease, or the time in the patient's life when they were most healthy? Does the aim of returning the patient to their previous level of health take into account changes in health that are due to natural aging (some diseases take a long time to cure or develop an effective method of management)? Restoration to the patient's previous level of health (or as close to the patient's previous level of health) seems to be a tall order to fill, even if one were able to determine what the previous level of health the patient should to be restored to.

It could be the case that medicine with a strictly restorative focus would fail in its attempts to restore individuals to (or close to) their previous level of health. If restoring an individual to their previous level of health is

unattainable and unrealistic, then it would most likely be even harder to restore an individual to a higher level of health than they had before presenting with a health problem. This leaves the goal, in strictly restorative medicine, of restoring an individual's health to a minimum level of health. The minimum level of health will be something that would need to be determined by medical professionals. However, we often expect so much more from medicine than simply restoring an individual to a minimum level of health. Given our expectations that medicine do more than simply restore an individual to some minimal level of health, and that medicine is not solely backwards looking, the goal or focus of medicine cannot be simply restorative.

The inclusion of preventative measures adds a forward looking perspective to medicine. By looking forward to avoid potential problems, medicine can help people to take measures to preserve their health. There is also the potential that by looking forwards the problem may be less harmful or more easily addressed, even if it cannot be avoided altogether. One example of this is whooping cough, which is a highly contagious bacterial infection that can be very harmful (or potentially fatal) to young children.[107] Since wide-spread vaccinations for this infection have taken place the numbers of children getting this infection have reduced drastically.[108] The vaccine has been highly

[107] NHS Whooping Cough, Accessed on March 3rd 2014 http://www.nhs.uk/Conditions/Whooping-cough/Pages/Introduction.aspx.
[108] However, recently we have seen outbreaks of whooping cough, but the numbers still remain much lower than they have been in the past. The question around the cause of these recent outbreaks lies in determining whether whooping cough has developed a resistance to our current vaccine, or if the recent resurgence is due to parents choosing not to vaccinate their children.

effective, but can fade with age.[109] Although an individual who has taken the vaccine may still get whooping cough in their adult life, they will be unlikely to suffer the same complications which they would likely suffer if they had caught this in their early childhood. Preventative measures are one aspect of medicine that helps to promote the health of individuals. There are other ways that medicine aims at health promotion, such as conducting studies and giving advice, based on the results, which can help individuals to maintain nutritious diets and make active lifestyle choices, helping individuals to improve their health. These promotional aspects are not just focused on the possible prevention of poor health, but also on helping individuals to maintain a higher level of health throughout their lifetime.

There is some discussion about what the scope of medicine covers. If the scope of medicine is too narrow, then somethings that we typically associate with medicine and medical interventions fall out. For instance, if the scope is narrowed to only include restorative treatments, then things like palliative and hospice care fallout, since those types of care do not and cannot restore the patient's health. However, if the scope of medicine is too broad then we run the risk of medicalizing the human condition.[110] In what follows there will be a slightly broader scope so that some aspects of public health might be included, like the use of the research conducted and suggestions made by healthcare professionals about possible lifestyle choices. I think that public health has a wider range than what is included here and that somethings are both fall into public health and personal health. Things like vaccines help

[109] NHS Whooping Cough, Accessed on March 3rd 2014 http://www.nhs.uk/Conditions/Whooping-cough/Pages/Introduction.aspx.
[110] Randall and Downie, 1996, 13 and 15.

prevent the individual from getting becoming ill, but they also work using herd immunity and are beneficial to the larger group as well. Research into diets and nutrition are important and can promote the individual's health generally, but at times dietary advice can help an individual to manage health conditions, such as, diabetes, diverticulitis, Cohn's disease, or celiac disease. Some of these conditions can be managed with medication and often require a special diet. Other health or cognitive issues can be caused by a deficiency in vitamins or nutrients. For these reasons, I think that health promotion should be included within the scope of medicine.

The focus or goal of medicine appears to be overall health promotion. If overall health promotion is the focus of medicine, then it would explain why medicine includes restorative, preventative and promotional aspects in both practice and research.[111] I argued above that the goal of medicine cannot be strictly restorative because we expect more from medicine than simply restoring patients to a minimal level of health and because medicine is not strictly backwards looking. Much of our medical research looks into causes and prevention as well as treatment or curative aspects of disease. If the focus of medicine were solely restorative this would not be the case, and all of the research attention would be focused on curative measures.

The goal of medicine is overall health promotion, but there are constraints on this goal. It is not the role of medicine to force overall health promotion on everyone. The way in which medicine promotes the overall health of the

[111] I am going to include health promotion in medicine because things like lifestyle choices and risks associated with them come up later in this thesis when discussing genetic screening for an inherited susceptibility to cancer. I also think that the scope of things to be included in medicine should be broad enough to make sure that palliative care gets included.

patient is constrained in the sense that medicine's role in the lives of individuals is to give the patient the information they need to promote their health, and to make available to the patient treatments for ailments aimed at restoring or improving the patient's health and preventative treatments aimed at avoiding possible health issues in the future. Medicine is constrained in the promotion of health by allowing individuals to make their own choices with regards to their lifestyle (including diet, recreation, and other choices which may have an impact on their overall health like living in areas with lots of pollution) and treatments for health issues which they may present with throughout their life.

A theory of health which does not focus solely on the absence of disease, illness, and injury or biological functioning, like the combination theory outlined above, can accommodate this more inclusive relationship between medicine and health. The concept of health includes more than just the absence of disease, illness, and injury and so it would make sense that medicine, which we associate so closely with restoring and preserving health, deals with more than just helping an individual regain their health after getting injured, or contracting a disease or illness. Medicine as focused on health promotion often takes into consideration more aspects of the patient's life than simply whether the patient is ill, diseased, injured or not functioning to the species typical normal functioning. Health promotion involves ensuring that the patient is able to have at least some of the capabilities outlined above. Many treatments involve helping the patient to continue participating in their day-to-day activities. For example, effective pain management not only helps the patient to feel better, but the effectiveness is

often measured by the patient's ability to complete their day-to-day activities. Pain management is good example because it treats only a symptom of a condition, but does nothing to cure the ailment that is causing the pain. The combination theory of health can better explain the inclusion of pain management than the biological functioning, or absence theories of health, since, strictly speaking, pain management does not treat the ailment that causes the pain.

Physicians and patients work together to determine whether a regimen of treatment is working effectively and one of the most common measures that a patient uses to determine whether the treatment is working effectively is whether they can carry out their planned daily tasks.[112] The thought that medicine has more to do with maintaining and promoting health then simply restoring health is seen in changes that have occurred throughout medicine and medical practices, such as changes in what is covered under the scope of cancer care.

III – Cancer Care

In recent years there has been a shift in the focus of cancer care. There has been an expansion of what precisely falls under the scope of cancer care. Cancer care no longer has a purely curative focus, but it has expanded its area of concern to include palliative care and living with cancer.[113] The cancer patient now has a more holistic treatment protocol which includes cancer treatments such as chemotherapy, radiation, surgery, and supportive care, but the patient can also receive palliative care without having to leave the

[112] Berlinger and Lederman, 2009, 19.
[113] Zahedi and Larijani, 2007, 17.

oncology ward or having their care transferred to another area of medicine. Research into possible causes and advancement in screening options also looks towards preventative measures. Identifying gene variants that indicate an inherited susceptibility to cancer and offering individuals with this risk advice to reduce their risk and a frequent screening regime can be seen as a preventative measure. There has also been some research conducted into treatments such as chemoprevention. I think that this shift in what gets included in cancer care supports the claims that I've made above about the aims of medicine. Moving beyond a strictly curative (restorative) focus to include things like living with cancer shows an interest in health promotion for the cancer patient.

Cancer care, and medicine more generally, aims at promoting a shared decision-making model for determining treatment for each patient. A shared decision-making model encourages the active participation of both the physicians (oncologists and where needed other specialists) and the patient in determining the course of treatment for that particular patient. The role of the physician is not simply to give the patient their treatment options and information that the patient is expected to use to make their own decisions independently. The physician's role includes giving the patient recommendations and advice based on the physician's knowledge and experience which is intended to aid in the patient's decision-making. The shared decision-making process involves active engagement by both the physician and the patient. The aim of the shared decision-making model is to help patients to make the best decisions for their treatment.

Different cancers do not respond the same way to treatment and the treatments do not respond the same way for every patient. The patient's course of treatment will need to be addressed and readdressed throughout their course of treatment.[114] It is for this reason that the physician's extensive experience is needed for the patient to make informed decisions about their treatment. The shared decision-making model allows patients to have both the information they need to address changes in their treatment and the advice and recommendations from their physicians, who has much more experience or exposure to dealing with cancer, to help them to make the best decisions they can. The recent shift from a curative focus to a more inclusive approach to cancer care and the inclusion of the shared decision-making model indicates that cancer care aims to promote the health of their patients more generally.

IV – Conclusion

There has been a shift in cancer care from a curative focus towards a more inclusive cancer care, which focuses on the promotion of the overall health of patients. This shift suggests that more than just the absence of disease, illness, and injury are important to the overall health of the patient. While the shift in cancer care is presented at the end of the chapter it caused me to ask the following question. If there is more to health than the simply the absence of disease, illness, and injury, then what exactly is health? This question then inspired an investigation into different theories of health. We looked at five of the main modern theories of health and determined that they were unsuccessful as theories of health because they did not sufficiently meet one

[114] Berlinger and Flamm, 2009, 19.

or more of the criteria for a successful theory of health. A successful theory of health must be able to accommodate our ordinary notions of health, it must be coherent, and it must be able to explain the normative significance that we assign to health. The last theory of health that was proposed was a combination theory of health, which included capabilities and the absence of disease, illness, and injury. A combination of these different aspects can accommodate our understanding and expectation of medicine and what medicine's responsibilities are. This combination theory can also explain the shift in the focus of cancer care and it can answer the question which this shift inspired: what is health? The combination theory of health will be used throughout the rest of this thesis. This will be the theory of health that will be in mind when discussing the relationship between health and well-being. In chapter three I give a brief discussion of how health can impact on autonomy. This theory of health is also discussed when looking at death and the dying process in chapter four. The individuals seeking genetic testing in chapter five need not be unhealth to seek out testing and the chapter will be written from the perspective of healthy individuals.

Health and Well-being

Health has an impact on many different aspects of an individual's life.[116] An individual's health state can put limitations on what they can do and the type of opportunities that are open to them. Because of this some might argue that health and well-being are the same thing. However, this is not the case: there is more to an individual's well-being than their health. Health may impact how well an individual's life goes for them, but it is not the only aspect of that person's life that determines how well their life goes for them. An individual may have great health, even if their life is not going particularly well for them. The converse of this can be true as well. I've stated that the individual's health can put limitations on what they can do or the types of opportunities that are open to them, but the health state of the individual need not *only* have a negative impact on their well-being. This shows that health is not the *only* determining factor in what makes a person's life go well for them. Health and well-being are not the same thing and the relationship between them is complex and intertwined.

In this chapter I intend to argue that health has an important impact on well-being, whether positive or negative. To do this I will begin by looking at different types of theories of well-being. I will highlight some of each type of theory's benefits and some objections against them. Once this survey is

[116] For the purpose of this chapter I will be using the term 'health' to refer to states of health and unhealthy. So, when talking about the health of the individual I will not be making a claim about their specific health state, unless otherwise indicated.

complete I intend to argue that even if health is *not* a constituent of well-being (and surprisingly it does not make it into many types of theories in its own right, and maybe this is correct).[117] Health has such a large causal impact on well-being that the relationship between health and well-being needs to be taken into consideration when developing policy and treatment guidelines, or determining what types of tests, treatments, and procedures should be offered through medicine and the healthcare system.

One might ask why we should look at well-being at all. Why not focus purely on health? I intend to argue that if we were to look at the base of two of the guiding principles in medical ethics, beneficence and nonmaleficence, we would find a concern for well-being.[118] The principles of beneficence and nonmaleficence can be thought of as imposing corresponding duties that aim

---

[117] I think that it might be correct not to assume that health is a constituent of well-being; that the value of health lies in it's contribution to an individual's well-being. Health may be non-instrumentally valuable. While I do not agree with the theory of health that Daniel M. Hausman employs, I do find his arguments for the non-instrumental value of health to be quite convincing. The question as to whether health is instrumentally or non-instrumentally valuable falls outside of the scope of this chapter and need not be answered for the arguments in this chapter to be valid. This chapter focuses on the relationship between health and well-being and the conclusion that this relationship is complex and intertwined still holds whether they are competing values or not.

[118] As noted in the introduction of this project it is generally accepted that there are four guiding principles in medical ethics. These principles are: beneficence, nonmaleficence, respect for autonomy, and justice. All four of these principles can be thought of as contributing to or involving a concern for well-being, but this contribution or concern come from different directions than beneficence and nonmaleficence. Respect for autonomy, which will be discussed in more depth in the next chapter, contribute to well-being in the sense that people tend to value their life following or being the consequence of their choices. While, justice concerns well-being in a slightly different way; justice is concerned with balancing competing claims to medical resources. It is not necessarily concerned with the well-being of a particular individual in the same way that benefiting or not harming that individual is concerned with the well-being of that particular individual. If we had unlimited medical resources, then we would want to make sure that everyone got everything that they needed to keep them healthy, thus positively impacting on their well-being. However, this is not the case. When it comes to justly distributing finite medical resources concerns for the expected benefit to the patient (the impact the treatment will have on patient well-being) comes into play along with concerns about the number of people who can also be treated with those resources.

towards promoting patient well-being. As medicine is focused on the promotion and preservation of patient health, and beneficence and nonmaleficence, in the context of medical ethics, at base are concerned with patient well-being, the relationship between health and well-being needs to be considered. The reasons for promoting and preserving health are derived from our positive duties to promote patient well-being. A sensible way to promote well-being is to give specific roles to certain groups of people. The role that those working in medical professions have in promoting well-being is to focus on the preservation and promotion of health.

I will argue that health has a big impact on individual well-being according to any type of theory of well-being that is used, meaning that health is an important factor no matter which theory of well-being is correct. I will be using the combination theory that I proposed in chapter one to investigate the relationship between health and well-being. Since health has such a big impact on well-being the principles of beneficence and nonmaleficence can be used to argue that well-being (possibly insofar as health is concerned) is an important consideration in medicine and medical care, no matter which type of theory of well-being is subscribed to. With this in mind there is no need for the project of this thesis to subscribe to a specific theory of well-being as health has an impact on well-being no matter which theory we are using.[119]

[119] Different theories of well-being may hold different views on the value of different health states. The value assigned to different health states does not change the impact that health has on well-being because having or lacking a valued health state will impact on that individual's well-being. If a theory of well-being were to hold that being in good health makes a person's life go well for them, then the individual's actual health state would impact on their well-being. The converse would also be true, if a theory of well-being holds that it is better to be sick, then the individual's actual health state would impact on their well-being.

This chapter will first look at the principles of beneficence and nonmaleficence and their role in our day-to-day lives and their roles in medicine. In section two I will then go on to give a brief survey of four different types of theory of well-being in order to better explain the relationship between health and well-being. The third section of this chapter will investigate the relationship between health and well-being. The final section will discuss disability studies and quality adjusted life years (QALYs). I will argue that these studies do not alter the analysis of the relationship between health and well-being that I conduct in this chapter. Both disability studies and QALYs presuppose a specific type of theory of well-being in the way that they are designed. QALYs assume that health states will always reduce an individual's quality of life or well-being, which I demonstrate need not always be the case. This kind of health measure assigns instrumental value to health based on its contribution to well-being. The analysis provided in this chapter makes no claim as to whether health is instrumentally or non-instrumentally valuable, which makes this analysis provide more versatile. While disability studies find that an individual's chronic illness or disability does not tend to result in a lower level of subjective well-being. These results are not contrary to the analysis that I have provided in this chapter. . I will conclude that the relationship between health and well-being is complex and intertwined, as health has an important impact on an individual's level of well-being.

I – Beneficence and Nonmaleficence

Beneficence and nonmaleficence are commonly recognised to be two of four guiding principles of medical ethics.[120] It is commonly thought by medical professionals and those working in medical ethics that beneficence and nonmaleficence are principles that do, or ought, to govern medical ethics. In our day-to-day life we often recognise that our duties of nonmaleficence, or our duties not to harm others, are obligatory. Beneficence, or our duties to benefit or help others, on the other hand, are morally permissible or praiseworthy and so may not obligatory, so in a sense this may not be a duty. Some argue that our duties of beneficence are obligatory in the same way as our duties of nonmaleficence, but many regard nonmaleficence to be obligatory and beneficence not.[121] They argue that a failure to abide by the principle of nonmaleficence, or one's duties not to harm others, results in doing something that is wrong, but a failure to abide by the principle of beneficence is more akin to missing an opportunity to help or benefit someone else. However, in medicine, we regard both to be guiding principles.

Why do we regard them differently in medicine than in our day-to-day lives? One answer to this question could have to do with the aim of medicine. In the previous chapter I argued that the aim of medicine is general health promotion, which includes preventative, restorative and promotional aspects. It can easily be seen that harming patients will not, generally, promote, restore, or preserve their health. The restoration, promotion, and preservation of health helps or benefits those whose health is being addressed. Physicians

[120] Beauchamp and Childress, 1994.
[121] Beauchamp, 2013, online.

and other medical professionals have a knowledge base that has been cultivated which makes them uniquely qualified to restore, preserve, and promote health within a hospital or clinic setting.

When we are adhering to our duties not to harm others (nonmaleficence) what we are really doing is ensuring that we do not reduce the other person's well-being through our actions. By harming another person we are having a negative impact on their well-being. Well-being is most often defined as what makes a person's life go well for that person. Harming an individual does not help that person's life go well for them, it does the opposite. Beneficence on the other hand is a duty or requirement that we should benefit or help others. For those who argue that duties of beneficence are obligatory there is often a method of restricting the scope of this duty, so that duties of beneficence are not too demanding. For instance, if the benefit to the other individual would be great and the cost or inconvenience to the helping individual is small, then it would be obligatory to help. While, on the other hand, if the cost to the helping individual were large, then helping would be permissible or praiseworthy but not obligatory. If it were the case that the helping individual could benefit someone, but at a very high cost to him/herself and the benefit to the other individual were small, it would seem that the helping individual is going beyond the scope of what is required of the helping individual.

If beneficence is not obligatory, but only permissible or supererogatory, then as ordinary everyday folk we are not generally *required* to increase or positively impact another individual's well-being through actively helping or

benefiting them,[122] but as ordinary everyday folk we can be said to have a responsibility or duty not to negatively impact another individual's well-being through harming them. However, the arguments presented bellow can show why beneficence can be more demanding on some individuals and particularly why it is seen as a duty in medicine, albeit restricted to patient health. As ordinary everyday folk we may not have the skills and knowledge that would help us to increase or positively impact another's well-being in certain ways. This is not to say that only physicians and medical professionals can help or benefit people in certain ways. It would seem like anyone would bear a responsibility to get help if they have found an individual injured and unable to call for help on their own, but possibly there is a responsibility to do more. If an individual were to possess a certain degree of knowledge and skills and found themselves in a situation in which those skills and knowledge could benefit another greatly, then the individual may bear some degree of responsibility to act. Seeking out and acquiring the extra knowledge and skills to help others strengthens our responsibility to help in situations that would require the acquired skills and knowledge. If an individual were to seek and acquire training in first aid they have taken on the added responsibility to aid others in emergency situations until help arrives. When seeking this type of training the individual has done so in part to have the knowledge and skills to help in those types of situations. This is also true for those who have undergone training and education to work in medical professions. Medical professions are based around helping people through

[122] The correctness or scope of this claim could depend on one's stance regarding whether duties of beneficence are viewed as permissible, supererogatory, or obligatory. As discussed above if duties of beneficence are viewed as supererogatory or permissible, then individual would not generally be *required* to adhere to them.

the restoration, preservation, and promotion of health. When entering into this field medical professionals acknowledge the added responsibility or obligation to help or benefit their patients through the restoration, promotion, and preservation of the patient's health.

Unlike ordinary everyday folk, physicians and medical professionals have special skills and knowledge that can help or benefit others in a certain way when they seek it. Physicians and other medical professionals have undergone training and have been educated in dealing with people's health. They have acquired the knowledge and skills that they need to help to restore, promote, and preserve the health of their patients. Medical professionals have in depth knowledge about how the body works and disease processes that make them better suited to addressing health issues for their patients. The types of knowledge and training that medical professionals receive is heavily focused on theories, methods, and norms of biomedical sciences. This focus on the biomedical sciences influences what types of information is seen to be important for assessing the health issues, like making a diagnosis, and determining the most appropriate course of action.[123] When people are in a state of unhealth, they have been injured or

[123] The focus on biomedical science as being the main source of knowledge in medicine creates an epistemic gap between the medical professional and the patient. This gap is in part the result of the medical professional likely having considerably more knowledge than the patient, but the gap grows wider when the medical norms deem some types or sources of knowledge as inappropriate for the field or not relevant. This type of issue can result in epistemic injustice and can ultimately impact on the patient's well-being, but that is not the focus of this chapter. Some of these issues are discussed a lot in phenomenological accounts of illness and there is a growing literature looking into epistemic injustice in medicine. Some attempts are being made to provide training to new medical professionals to attempt to combat this, or reduce the epistemic injustice that is currently present in medicine (Buchman, Ho, and Golberg, 2017, 32 and Carel and Kidd, 2017, 344). There will be further discussion about epistemic injustice in the next chapter. In this chapter I am arguing

suffer from some ailment like a disease or illness; they go to a physician seeking that physician's training and knowledge to help them. By adhering to beneficence and nonmaleficence the physician and/or other medical professionals seek to positively impact the ailing individual's well-being through the use of their knowledge and skills by restoring, promoting, and preserving the ailing individual's health.

It may seem that with their vast amount of knowledge physicians and medical professionals may be in a position to benefit or help people by increasing their well-being in other ways, not just through promoting and preserving patient health. If the aims of medicine can be explained as following from the aim to promote well-being, as I have argued is the underlying concern of the principles of beneficence and nonmaleficence, then one might ask why this broader aim does not generate broader duties. However, it seems that it would not be an effective use of a physician's time, skills, and knowledge to help a young patient with his algebra homework (if homework contributes to that patient's well-being) when there are many other uses for the physician's knowledge and skills that would require the physician's time. Medical professionals time is a limited resource and their skill set makes them uniquely qualified to benefit people in a certain way, namely through their health. This being the case a just allocation of medical professionals' time would indicate that that time should be spread out to help other patients too.[124]

---

that due to the knowledge and skills that medical professionals have they incur a stronger duty to benefit or help their patients with regards to the patient's health.
[124] One might say that medical professionals take an oath to benefit their patients. However, the method of benefitting patients is restrained to health related issues.

Physicians and medical professionals focus on restoring, promoting, and preserving health as a means of promoting well-being because of the content of the knowledge and skills they have acquired. Their training is such that it gives them a distinctive means of promoting well-being through health that most other people do not have. Because of their unique knowledge and skills with regards to anatomy, illness, and disease, their time and abilities should be focused towards health. The needs and benefits that medical professionals are uniquely qualified to deal with are needs and benefits of a certain sort, those that pertain to human anatomy, disease, illness, and other health related requirements.

The promotion of well-being through health may not be as straightforward as one may think, since the relationship and interaction between health and well-being may be more complex. The complexity of this relationship and the interaction between health and well-being does not and likely should not have a simple background theory that is used to make decisions or determine actions. When considering what ways medical professionals can benefit and help their patients it appears as though their specific knowledge and skills determine how they should help or benefit their patients. Another way to look at it is to think about how the field of medicine has been segregated. There are many different roles or sub-disciplines in medicine which all have

---

There are many things that would or could benefit patients that we would not expect medical professionals to do and the oath taken is not intended to require medical professionals to benefit their patients in any and all ways. For instance, we would not expect medical professionals to find and help pay for better housing arrangements for a patient who is living in substandard housing, but we can expect them to fill out the appropriate paperwork so that the patient could apply for assisted housing. The same can be said for a patient who has lost their job due to a medical issue; we would not expect the physician to find them a new job or offer financial aid, but we can expect the physician to fill out the required paperwork so that the patient can receive benefits while they are ill or begin the process of getting social support for a disability.

different jobs or tasks. There is certainly overlap in much of the earlier training that medical professionals undergo, but once they've chosen their specialisation the overlap in knowledge and skills stops.

In a medical institution, such as a hospital, there are many different medical professionals. For instance, there are nurses (even in nursing there are different specialisations), medical technicians (for example imaging technicians, those that work in various labs, etc.), and then there are those that work in other specialities who may focus on one disease group or one organ system. Many, if not all, of these different medical professions share a foundation of knowledge (for example, human anatomy). They may have all learned a skill during their training, like how to draw blood. For some this skill would have been a requirement more akin to a formality, but for others this skill will be the focus, or one of the many duties, of their future career. A physician and a nurse may have both learned how to draw blood, but the nurse is the one who will hone the skill and use it most frequently. Because of this it would be the nurse that most would expect or prefer to draw their blood, not the physician. For the physician it seems like the skill, of drawing blood, is more of a requirement of formality than a skill that must be honed and perfected. The overlapping areas of training allow medical professionals to have a foundation for working as a team, which is largely what a hospital and medical profession is. Since the work is segregated in this manner each individual has a select set of tasks, roles, and knowledge they are required to contribute. There are only certain ways that each are expected to benefit or help patients, so there are only certain ways that each individual can restore, promote, and preserve health and thereby promote well-being.

II – Well-Being

There are several types of theories of well-being and much discussion on how they should properly be classified.[125] This is a very interesting debate, though it is not particularly relevant for the following discussion. Generally speaking most theories of well-being fall under four headings based on their similarities. Derek Parfit describes three types of theories of well-being in "What Makes Someone's Life Go Best"[126], but I will be considering four general types. The theories of well-being surveyed in this chapter are as follows: hedonist theories, desire satisfaction theories, objective-list theories, and hybrid theories. The theories that Parfit has classed as falling under the same categories often have similarities at a fundamental level and often have to try to address similar objections. This is not necessarily the case with hybrid theories. The common feature that hybrid theories share is that they attempt to merge strengths from other (sometimes competing) theories to avoid or address objections to either of the singular theories with the aim of making a stronger cohesive theory.

I will give a survey of the main features and objections to these four types of theories. I will also give an example of each of the types of theories discussed. The selection of the example theory is not to make any claim that the example

[125] Many have argued that theories of well-being should be classified into those that are subjective theories, which claim that constituents of well-being are attitude dependent, and objective theories, which claim that the constituents of well-being are attitude independent. However, this way of classifying theories has been brought into question. Guy Fletcher argues that theories should be classified based on whether the theory is enumerative or explanatory. According to Fletcher enumerative theories specify what contributes to well-being, while explanatory theories "aim to explain why something enhances well-being." Fletcher, 2013, 206.
I will be using Parfit's categories because I believe them to be more fine grained than classification systems that only have two groups and because I think that grouping theories together based on core features can be helpful.
[126] Parfit, 2012, 294.

theory is of a particular interest to looking at the relationship between health and well-being. Instead the intent is to give a concrete example of what a theory of a particular type would look like and to provide a clear view of how the objections to that type of theory would unfold. One reason to include objections to hedonism, desire satisfaction, and objective list theories, is that this will help to illustrate the motivations for hybrid theories. If I were to only include the main features of each theory without stating the objections, it may not be immediately apparent what the motivation for hybrid theories might be. Once this survey is complete the aim is to have a general understanding of what these theories are and how these types of theories might address health in relation to well-being. In the third section of this chapter I intend to investigate the relationship between health and well-being using the survey of types of theories of well-being. I will argue that health has an impact on well-being even if the type of theory does not deem it to be a constituent of well-being. Since health has an impact on well-being for all four types of theories I will survey, it would seem that no matter which type of theory of well-being one subscribes to, or is correct, health has an important impact well-being.

II.I – Hedonist Theories of Well-Being

Chris Heathwood claims that hedonism is one of the simplest, oldest and historically most popular answers to the question of what makes a person's life go well for them.[127] Hedonist theories of well-being are mental state theories. According to hedonist theories, what makes a person's life go well for them is having mental states such as pleasure or happiness and avoiding

[127] Heathwood, 2010, 4.

mental states such as pain or unhappiness.[128] In his book *Normative Ethics* Shelly Kagan identifies four different hedonist views:

- Psychological hedonism – claims "as a matter of empirical psychological fact – everyone's ultimate goal is to pursue their own pleasure and minimise pain."
- Ethical hedonism – claims "what everyone should do morally is to try to maximise pleasure and minimise pain."
- Value hedonism – claims that pleasure is the only intrinsic good and pain is the only intrinsic evil.
- Welfare hedonism – claims that well-being consists solely in the presence of pleasure and the absence of pain.[129]

Our main concern for the purpose of this survey is with the last type of hedonism Kagan outlines because of direct reference to well-being.[130] However, according to Heathwood historical hedonists believed that psychological hedonism establishes the evaluative claim in welfare hedonism.[131] According to welfare hedonism an individual's well-being is equal to the balance of pleasure over pain that person experiences through their life. On a simple hedonist view[132] well-being can be determined by a simple equation:

---

[128] Kagan, 2009, 253.
[129] Kagan, 1998, 31.
[130] As we have seen there are many different types of hedonism and others may be pertinent to thinking about health. However, taking into consideration the focus of this chapter and space I will be focusing on welfare hedonism. To give a detailed analysis on how each type of hedonism may play a role in thinking about health is beyond the scope of this project.
[131] Heathwood, 2010,4.
[132] This is sometimes referred to as quantitative hedonism.

(duration of pleasure x intensity of pleasure)

- (duration of pain x intensity of pain)

Individual's level of well-being [133]

One of the main objections to this type of theory is that any and all pleasures and pains are counted equally: they each get put into the equation the same no matter the source of the pain or pleasure. This type of theory is all about quantity, but according to the objection some pleasures and pains should count for more or are more valuable. John Stuart Mill proposed that some pleasures are of a higher quality and those are the pleasures that one should seek, since the higher quality pleasures are worth more.[134] To address this issue some hedonists followed Mill and proposed that the quality of pleasure and pain should be considered when measuring well-being. Not only should the duration and intensity be included in the calculation but there should be some quality rating which makes its way into the figure as well.[135]

Even with this alteration many argue that Nozick's experience machine thought experiment illustrates that there is more to well-being than having the right sorts of mental states. They argue that a life plugged into a machine designed to give the individual any experiences he or she would like to programme into their life within the machine, is not a life that is going well for that individual. We don't value just having the mental states, but we value having done the things that we have experiences of. We value that our experiences match up with actual states in the world. [136] This is not a

[133] Kagan, 1998, p 31.
[134] Mill, 2001, 7-9.
[135] Kagan, 1998, 32.
[136] Kagan, 2009, 253.

requirement of hedonism and according to many this is why hedonism fails. It cannot make adequate sense of the value that we put on having our inward experiences match actual states of the world. If all that matters to one's well-being are the inward experiences, then the actual states of the world do not have to be there, and strictly speaking they do not matter to well-being. To many this is problematic.

Kagan argues that an adequate theory of well-being must get the 'inside' as well as the 'outside' right. According to Kagan's metaphor the 'inside' has to do with having the correct metal state, while a theory that has the 'outside' right it matches up with the actual world. The theory is one that picks out things that are objectively good.[137] Hedonism arguably gets the 'inside' right, but it is important that the 'inside' and 'outside' match, and hedonism does not provide this.

II.II – Desire Satisfaction Theories of Well-Being

Desire satisfaction theories hold that the satisfaction of an individual's desires is what determines her level of well-being. Desire satisfaction theories hold that it is not the experience of your desires being satisfied that contribute to well-being, but the fact that the desire is actually satisfied that contributes to well-being.[138] On the simplest and most often rejected version of this type of theory, desire satisfaction is all that matters. This version of desire satisfaction theories can be referred to as "unrestricted".[139] The main objection to this version of the theory is that all and any desires that are satisfied contribute to

[137] Kagan, 2009, 255.
[138] Kagan, 1998, 36.
[139] Kagan, 1998, 37.

an individual's well-being and it does not require that the individual have knowledge that the desire was satisfied for the individual to benefit from an increase in well-being.[140] Since all and any desires would be included an individual could desire something that has no impact on their life, which if satisfied would contribute to their well-being. For instance, imagine that an individual desires some astrological theory to be true and unbeknownst to him the theory is proven true. On this version of desire satisfaction theory this would have a positive impact on his well-being. Many think that this version can include too many desires that have no impact on the individual's life and since the desires are so far removed from the individual's life it should not have an impact on the well-being of the individual. How could the truth of some astrological theory make the individual's life go well for them? Another objection to this simple version of a desire satisfaction theory is that the individual is not even required to know the desire has been satisfied to benefit. These objections call for some way of restricting the types of desires that contribute to well-being.[141]

One attempt to restrict the desires that count is to say that only desires that an individual has that concern or are directly related to the individual's life contribute to well-being.[142] Kagan refers to views which apply this restriction to desires a "restricted" desire satisfaction theory.[143] This restriction could be used to attempt to address the two objections raised above. Restricting the desires that contribute to an individual's well-being to only those desires that concern or are directly related to their life would exclude desires for things

[140] Kagan, 1998, 37.
[141] Kagan, 1998, p37-38.
[142] Kagan, 1998, 38.
[143] Kagan, 1998, 38.

that will have no impact on the individual's life. This move could also partially address some of the concerns about desires being satisfied without the individual's knowledge. One might think that if the desire is required to concern or directly relate to an individual's life that it would be unlikely that it could be satisfied without the individual's knowledge. However, this may be true for some desires that concern or are directly related to an individual's life, but this is not necessarily true for all of the desires that fall under this restriction. This type of theory relies on an individual's actual desires, so along with well informed and rational desires, there would also be desires based on misinformation, misunderstanding, errors of reasoning, bias, and inexperience.[144] For any of these reasons or any combination of these reasons an individual may have a desire for something that if satisfied would result in something that is pre-theoretically not good for them or may in fact be rather bad for them.[145]

It is at this point in this investigation where it can be helpful to distinguish between different types of value: instrumental, non-instrumental, and overall value. Something can be instrumentally valuable in that achieving it is valuable in that it helps the individual to achieve something else of value. While something that is non-instrumentally valuable is valuable for its own sake. Overall value is arrived at through the combination of instrumental value and non-instrumental value. These different types of value correspond to similar types of disvalue. Desires can be such that they relate to these different types of value. An example of this might be an individual who really likes computer security systems. This individual enjoys finding

[144] Arneson, 1999, 124.
[145] Lauinger, 2013, 274.

vulnerabilities in these systems and she would like to pursue a career relating to computer system security. In her spare time she hones her skills by actually finding vulnerabilities in computer security systems. She is aware that if caught she could get into trouble and even be punished for doing this. To pursue her career goals she applies to university, but as her luck would have it she gets caught for breaching a system. She is punished for this violation and the opportunity to go to university is now restricted or closed to her. In this example it would seem that her pursuit of the desire to find vulnerabilities in computer security systems has landed her in a situation that does not help her life go well for her, particularly since it frustrates her desire to go to university. So the question is: how can the satisfaction of the desire to breach computer security systems contribute to her well-being when it has resulted in punishment and frustrating her desire to go to university?

It is true that punishment usually detracts from the punished individual's well-being for some amount of time, but the disvalue involved in this example may only be instrumental. This individual's desire to go to university may be frustrated, but the desire was only in place because she wanted to pursue a career in computer system security, so the desire only had instrumental value to begin with. Being caught does not in itself prevent her from satisfying her career goal, which she values for its own sake. In this case being caught could have served as an audition, since she had successfully infiltrated other security systems in the past, thereby landing her the career that she was aiming for to begin with, thus satisfying a desire that had non-instrumental value.

Desires arrived at through misinformation, confusion, false beliefs, prejudice, bias, errors in reasoning, or inexperience appear to be mistaken and potentially may have a negative impact on well-being. However, according to a desire satisfaction theory of well-being the satisfaction of these mistaken desires should contribute positively to the individual's well-being. Here is where the distinction between types of values comes into play. If the achievement of some desire results in disvalue that is purely instrumental, then the case can be made that the achievement of that desire does not negatively impact on the individual's well-being. However, if the desire that one is seeking is of the non-instrumental type then this worry may still be relevant. In cases of mistaken desires it seems as though had the individual known, or reasoned differently they may not have had that particular desire. For example, imagine an individual who believes that polar bears are gentle friendly creatures and who desires nothing more than to pet or play with a polar bear. The individual is a polar bear enthusiast who loves everything about polar bears and wishes to engage with them. In this instance one might assume that if informed of how dangerous a polar bear is, the individual is likely to change her desire to pet or play with the polar bear. Based on this new information the individual may still love polar bears and want to be close to one, but she now desires to see one in the safety of a zoo or one of those winter excursions that take tourists in specialised vans to see polar bears in their natural habitat.

Now if the individual having the new information still desires to pet or play with the polar bear it appears as though the desire is not mistaken, but

defective in some way.[146] Even with the knowledge that petting a polar bear is rather risky and very likely life threatening the individual still desires it. This new information about polar bears has done nothing to dissuade the individual from having or attempting to pursue this desire. It's not that this desire is risky or dangerous that makes it defective, but that it is completely impervious to new information, the individual has not taken the information and risk into consideration when forming or evaluating the desire.

According to a desire satisfaction theory of well-being (even on a "restricted" version as opposed to a simple/"unrestricted" version) it would appear as though the satisfaction of the desire to engage with the polar bear would contribute to the well-being of the individual, while the actual act of engaging with the polar bear would be dangerous and potentially harmful to the individual (which would intuitively lead one to believe it would have a negative impact on the individual's well-being).[147] Although mistaken desires and defective desires can fall into the category of desires that contribute to well-being, on a "restricted" view there still seems to be a problem. It seems as though there may be more required of a desire satisfaction theory of well-being than the restriction of desires to include only those desires that have a direct impact on the individual's life.

---

[146] Lauinger, 2013, 274.

[147] Desire satisfaction theorists may argue that the defective desire objection is not as strong as one might think. The individual may have a non-instrumental desire for something risky, like engaging with polar bears, but the danger and potential harm are instrumental. So, the satisfaction of the desire to engage with polar bears still would contribute to the individual's well-being. However, in the polar bear example the damage that the individual would likely endure if she pursued the desire would likely be significant and result in her being unable to fulfil many other desires she might have, if of course she were to survive her encounter. This being the case it is likely that the disvalue would be more significant than mere instrumental disvalue.

One way that this concern might be addressed is by turning from theories that focus on actual desires held by the individual to hypothetical desires, which are desires that the individual would hold under certain conditions[148] (those conditions are often outlined by the specific theory). Some theories specify that the desires that contribute to an individual's well-being are those desires that one would have if they were fully and vividly informed.[149] However, Lauinger argues that even if the desires that count are only those that are fully and vividly informed "at least some defective desires would persist."[150]

Another approach to addressing the problem of mistaken and defective desires is to stipulate that the desires that contribute to one's well-being are those that an ideal version of oneself would have. An ideal version of oneself would be fully informed, thinking clearly, free from prejudice and bias, and be free from various types of irrationality or error.[151] Kagan argues that an ideal version of oneself may desire things because they see that there are things that are objectively good for one to have—which leads to an objective list theory of well-being.[152] This speculation aside, there are several objections that can be raised against informed and/or ideal desire satisfaction theories.

One objection is that the fully informed version of oneself may desire things that actual version of oneself would not actually desire. There is the possibility that through becoming fully informed that version of oneself may become sufficiently different from one's actual self that the desires the fully

[148] Lauinger, 2013, 274.
[149] Lauinger, 2013, 276.
[150] Lauinger, 2013, 276.
[151] Kagan, 1998, 38.
[152] Kagan, 1998, 39.

informed self would have would not match up with the desires that the actual self would have, the worry in this case would be that the desires that contribute to the well-being of the individual might be vastly different from the desires that the actual self would have. In this way the actual self may be alienated from the desires which if satisfied would contribute to their well-being.[153] Whether this objection applies depends on what is meant by fully informed. If fully informed means that the fully informed version of oneself has the relevant facts about possible desires, like say the fully informed version of oneself had the relevant facts about polar bears (to stick with the example from earlier), then desiring to be safely near polar bears would be a fully informed desire. This full information may include not only facts about polar bear behaviour, but also the fact that there are exhibits in zoos and tourist trips to see polar bears. This type of fully informed version of oneself would not likely desire things that are vastly different from what the actual version of oneself would desire.

However, if what is meant by fully informed is stronger than just relevant facts, but includes every possible outcome to all decisions and what it would *be* like to live any possible life that an individual might lead, then there is certainly a possibility that this stronger meaning of a fully informed version of oneself would desire things that are or may possibly be vastly different from those things desired by the actual self. This could lead to things contributing to an individual's well-being that are or may not be desired by

[153] The separation between what the actual individual values or has positive attitudes towards and what makes their life go well for them is often referred to as the alienation objection. The alienation objection is typically raised against objective list theories. However, as I will explain, it would also apply to what I will refer to as the stronger version of fully informed desire satisfaction theory.

the actual self. The first (weaker) sense of fully informed looks as though it is closer to avoiding some mistaken desires and possibly some defective desires as well. If this is the case, then it would seem that the only difference in desires between the fully informed self (in the weaker sense of fully informed) and the actual self are the desires that this fully informed version of oneself sees as mistaken or defective.

The second (stronger version) of fully informed sounds more like an ideal version of oneself than merely fully informed. Arneson argues that to become fully informed in the second (stronger) way described above would be impossible.[155] Fully informed in this stronger sense requires that the fully informed version of oneself would know what it would *be* like to live any possible life that the individual might live. Knowing what it would *be* like to live any possible life that an individual might have seems to have the requirement that the fully informed version of oneself would have experienced all of these possible lives. So, the ideal version of oneself would need to be less than fully informed or the experience requirement, of "what it would be like to live any possible life you might lead"[156], would need to be removed. With this removed Arneson argues that the ideal version of oneself and the actual version of oneself would not be sufficiently different in what they desire.

I think that between an 'ideal' version of this theory and a fully informed version (in the first weaker sense), the fully informed version would be able to address objections better. The 'ideal' version of a desire satisfaction theory

[155] Arneson, 1999, 129.
[156] Arneson, 1999, 129.

appears as though it may be more subject to the alienation objection than the fully informed version of the theory. I think that even with the experience requirement removed like Arneson suggests, the knowledge of every possible outcome to all decisions and any possible life the individual might lead could still result in the 'ideal' version of oneself desiring things that are vastly different from the actual self. However, I agree with Lauinger that a weaker version of fully informed desire satisfaction theory still leaves some room for mistaken and defective desires.[157]

II.III – Objective List Theories of Well-Being

Objective list theories of well-being claim that there are things that are good or bad for an individual regardless of whether the individual desires or values them. There are things that make a person's life go well for them independent of that individual's attitudes towards those things (whether the individual wants, desires, or likes the things on the list).[158] On this type of theory there is a list of multiple goods that are said to be valuable independently of our attitudes towards them, and contribute to well-being, and it is said to be an objective fact that the goods on the list are valuable.[159] The possession of these goods indicates how well off an individual is. The more goods from the list that an individual possesses, the better off she is. On some objective list theories the items on the list may contribute to well-being more or less than other items on the list. For an objective list theory to give a full account of well-being it must include a list of goods which contribute positively to well-being as well as a list of things which contribute negatively

[157] Lauinger, 2013, 276.
[158] Kagan, 1998, 39.
[159] Kagan, 1998, 39.

or reduce well-being.[160] Many supporters of objective list theories only include a positive list in their theories, which Fletcher argues only gives half the constituents of well-being.[161]

A positive way to regard this type of theory is that it gives a clear indication of what contributes to well-being for everyone. What contributes to an individual's well-being is having the things on the list. This allows us to have an account of what makes a person's life go well for them that we can apply to all persons, making the measure of well-being comparable between people everywhere. However, this leads to one of the strongest objections against this type of theory. Many argue that since the list of constituents of well-being is attitude independent there could be people who possess all the constituents of well-being, but are unhappy or miserable.[162] For these people it seems as though intuitively we would not want to claim that they have a high level of well-being, or that their life is going well for them. It appears as though objective list theories alienate people from what contributes to their own well-being.[163] According to the objection, by not taking into consideration people's desires and attitudes this type of theory denies the individual the ability to determine for themselves what is good or bad for them. Although Arneson supports an objective list theory he argues, objective list theories (or any objective theories of well-being) "denies the claim of agent sovereignty, asserts the claim of realism about prudential value (which includes the former denial), and asserts that there exists a plurality of types of goods."[164]

---

[160] Fletcher, 2013, 214-215.
[161] Fletcher, 2013, 214-215.
[162] Kagan, 2009, 254.
[163] Fletcher, 2013, 215.
[164] Arneson, 1999, 117.

Arneson argues that since an objective list theory asserts that there is a fact of the matter about what the constituents of well-being (the objective goods that make a person's life go well for them) are then an individual can be mistaken about what is good for them, and that individual's evaluative perspective does not fix what is good for them.[165] The individual's evaluative judgements about the objective goods plays no role in determining what makes their life go best for them. Many individuals who object to objective list theories use these very arguments against this type of theory. However, Arneson argues that, while true, they are not problematic because there will be some constituent on the list that concern the attitudes of the individual.[166]

Guy Fletcher takes a different approach, he argues that the alienation charge can be avoided by compiling the right objective list. Fletcher says that the types of thing on the list should be the types of things that are attitude-sensitive. The constituents of well-being are things that have a pro-attitude built into them. In his paper "A Fresh Start for the Objective List Theory of Well-Being" Fletcher suggests a partial list (his list only covers positive constituents of well-being, which he claims is not exhaustive). Fletcher's list includes: achievement, friendship, happiness, pleasure, self-respect and virtue.[167] Fletcher argues that each of these constituents of well-being have pro-attitudes as necessary components built in by virtue of what they are. For example, friendships require a desire and positive attitude towards the relationship for it to be a friendship. If an individual neither wanted friends nor had any positive attitudes towards the other person, then the relationship

[165] Arneson, 1999, 116.
[166] Arneson, 1999, 117.
[167] Fletcher, 2013, 214.

between the two could hardly be regarded as a friendship. Since the goods on the list would be attitude sensitive, Fletcher argues that this type of objective list theory would avoid the alienation objection.

I think that Fletcher's objective list theory does address the alienation objection better than other objective list theories. If an individual were to possess a constituent of well-being there is a pro-attitude built into the possession of that item by virtue of what that item is, so the individual could hardly possess that item without exhibiting the pro-attitude that is built into that item. However, Fletcher's attitude sensitive constituents of well-being may have a pro-attitude built in, but an individual may not have a pro-attitude towards the item that she possesses. For example, an individual may have friendships, but not regard friendships as being particularly important or valuable, or an individual may publish a paper in an academic journal, but not believe it to be particularly good, so they do not believe it to be an achievement. In both of these cases the individual possesses a constituent of well-being, but does not regard it as something to be valued or lacks a pro-attitude toward possessing that item. This being the case one might argue that there is still an aspect of the alienation objection that has not been addressed by the move to attitude sensitive constituents of well-being.

II.IV – Hybrid Theories of Well-Being

The defining characteristic of hybrid theories is that these theories attempt to combine aspects from theories of other types to address objections. Hybrid theories attempt to combine strengths from different theories to make a coherent theory of well-being while avoiding the weaknesses of the

individual theories that are combined. To explain the motivation for seeking to create a hybrid theory I will give a brief reminder of the strengths and weakness of the types of theories discussed so far.

As Kagan pointed out in his paper "Well-Being as Enjoying the Good", hedonism appears to get the 'inside' right because it focuses on the value of having the right sorts of metal states, but we value more than having the right sorts of mental states: we also want the 'outside' to match.[168] According to Kagan, for a theory to have the 'outside' right it must relate to how things actually are in the world. According to this metaphor an objective list theory that picks out the correct set of objective good may have the 'outside' right, but does not consider the 'inside' at all, while hedonism gets the inside right, but does not match up with the 'outside'.

Desire satisfaction theories may do a fine job of addressing hedonism's weaknesses, but some of the main objections against this type of theory are those concerning mistaken and defective desires. The move to fully informed or ideal desire theories attempted to address this issue, but failed to adequately address the objection or introduced further objections which may or have resulted in unsatisfactory attempts to address them.

Objective list theories of well-being do not need to worry about mistaken and defective desires because there is an objective list of what is good or bad for a person, which applies to everyone. The main objection against these types of theories is that since the objective goods are attitude independent an individual can be seen as having a high level of well-being due to possession

[168] Kagan, 2009, 253.

of the constituents of well-being, but still be miserable or unhappy. It seems that the individual does not have a life that is going well for them. This type of theory addresses the objection applied to desire satisfaction theories about defective and mistaken desires by having a list of things that are objectively good for an individual, but in many instances this answer then leads to the objection that it alienates people from what constitutes their well-being. This theory does not appear to take the individual, as a unique person with desires, dreams, goals, ambitions, likes, and dislikes, into account when determining whether their life is going well for them. How can an individual's well-being be determined without taking into account that they are a unique person? Hedonism and desire satisfaction theories do this to varying degrees, or at least with different focuses.

Looking at these different types of theories we can see that a combination of types of theories could help to address these objections. With each different type of theory it appears as though it has a solution to the main objection of one of the other theories, but this solution has opened that type theory up to a different objection which another type of theory seems to address quite well. The most common combinations of types of theories are an objective list theory combined with either a desire satisfaction theory or a hedonist theory. In this chapter I have only given a general account of types of theories, and any fully developed hybrid theory would be much more specific.

In cases where one has made an attempt to combine a desire satisfaction theory with an objective list theory the new hybrid theory claims that there is a list of objective goods which if desired and obtained will contribute to the individual's well-being. William Lauinger proposes a hybrid theory of this

type in his paper "The Missing-Desire Objection to Hybrid Theories of Well-Being".[169] He argues that all humans have a stable desire for the basic goods (the items on the objective list) and because they have this stable desire the alienation objection will not hold. An individual's level of well-being is determined by this stable desire for the basic goods and the individual obtaining the basic goods. Lauinger argues that this stable desire is in all humans and gives explanations for individuals who appear to lack a desire for these basic goods by arguing that these individuals often or almost always desire something else more.[170] Cases of individuals who do not have a stable desire for the basic goods are very rare and in these very rare cases he argues that the basic good that is not desired does not contribute to that individual's well-being.[171]

Another approach to making a hybrid theory of well-being is to combine a hedonist theory with an objective list theory. In these types of hybrid theories there is a list of things that are good for a person and for anything on the list to contribute to the individual's well-being they must enjoy or get pleasure from having it. Shelly Kagan puts forth a theory like this in "Well-Being as Enjoying the Good". According to Kagan's theory there are objective goods and one must have the right sort of attitude towards that objective good for it to contribute to their well-being. It is a matter of both possessing the objective good and taking pleasure in it that contributes to an individual's well-being.[172] Kagan also argues that an objective good can be possessed in

[169] Lauinger, 2013.
[170] Lauinger, 2013, 280.
[171] Lauinger, 2013, 283.
[172] Kagan, 2009, 255.

degrees[173] and that it must be the cause of the pleasure for it to contribute to well-being.[174] "According to this view well-being requires taking pleasure in things that are *in actual fact* objectively good."[175]

These are just two brief examples of hybrid theories and how they could be combined. There are many possible ways to combine different hybrid theories just as there are many different versions of the other theories discussed above. Each of the different versions of each type of theory of well-being will have its own strengths and weaknesses.

This completes the survey of different types of theories of well-being. From this survey I will now address how these different theories would treat health and how health would impact well-being on each of these theories.

III – Well-being and Health

Well-being is a property of the whole life of the individual in question, and the individual's health has a bearing on many aspects of their life and longevity. A healthier life or lifestyle can have an impact on how long that individual might live and this will have a bearing on the individual's well-being. States of health or unhealth impact an individual's physical and mental abilities and can also affect an individual emotionally. People's physical, mental, and emotional states impact not only what they can do, but also how they experience things. For instance, suppose an individual is suffering from depression. The feelings of hopelessness that are often associated with depression can and often do influence how that individual perceives

[173] Kagan, 2009, 256.
[174] Kagan, 2009, 258.
[175] Kagan, 2009, 260.

situations around her and what decisions she is going to make. She may avoid making goals because she may perceive it as hopeless to even try to achieve them. The way that this individual perceives situations has an impact on how she experiences them, and this in turn has an impact on what she can do. The individual could be capable of achieving some goal, say writing a great novel, but because of her feelings of hopelessness she does not even try. With a physical ailment it can sometimes be easier to see the impact that it may have on an individual's well-being. Looking at how health can impact on the life of an individual let us now consider how different types of theories of well-being would address health.

In the previous chapter I outlined the combination theory of health. I argued that health is the absence of disease, illness, and injury and includes capabilities to function such as: mobility, "being able to move from place to place"[176]; "being able to avoid unnecessary or nonbeneficial pain and to have pleasurable experiences"[178]; "[b]eing able to live out to the end of a complete human life, as far as possible; not dying prematurely, or before one's life is so reduced as to not be worth living"[179]; having the ability to form future looking plans and desires; and having the ability to laugh[180] and form social bonds or attachments if one chooses to do so. I think that this combination theory of health can best explain the complex relationship between health and well-being. In this section I will use the combination theory of health to investigate the relationship between health and well-being. As I have stated

[176] Nussbaum, 1992, 222.
[178] Nussbaum, 1992, 222.
[179] Nussbaum, 1992, 222.
[180] Nussbaum, 1992, 222.

above, an individual's health can impact on their life in many different ways. The following analysis will provide support for this claim.

On a hedonist theory of well-being health would not be constituent of well-being on its own. The relationship between health and well-being may be seen as a straight forward matter of whether an individual's state of health is causing them pain or possibly preventing them from feeling pleasures. A poor health state may include pain or discomfort, though pain is not a necessary feature of poor health. However, the impact of health on well-being in a hedonist theory is not only limited to pain. A state of unhealth may have an impact on how much pleasure an individual gets out of something.[181] Even on a quantitative hedonist theory a state of poor health, say a state in which an individual feels constant fatigue, could reduce the intensity and in this case possibly the duration of some pleasure that the individual experiences. The intensity and duration of the pleasure would be used in the calculation to determine the individual's well-being; this being lessened by constant fatigue would result in a lower level of well-being than that which would be experienced in a better health state. Another example is one of slight hearing loss. This is a condition that is not necessarily painful, but can have an impact of the intensity of some pleasures. A lower intensity of pleasure when put into the calculations to measure that individual's well-being would result in a lower level of well-being. If this is the case for states of unhealth, then one

[181] This is not to say that the individual's health state will have an impact on all experiences of pleasure. Depending on the health state it may impact few or many of the individual's experiences of pleasure. I do not intend to argue that a health state would result in all of an individual's experiences of pleasure having a loss of intensity or duration, but I would argue that their health state would impact some subset of their pleasure experiences and this subset may be determined by the health state in question.

could reason that states of health may result in a high intensity and duration of pleasures for that individual. This would imply that states of good health would in a roundabout way contribute to well-being even if it is not one of the two constituents of well-being. This current analysis may be more influential on a qualitative hedonist theory.

On a qualitative theory pleasures and pains have a quality rating which gives some pleasures and pains more weight than others in calculations of well-being.[182] On this view health states which may limit one's access to engaging in things that produce a higher quality pleasure could result in lower levels of well-being, as not only is the individual deprived of higher quality pleasures, but, as I've argued above, the intensity and duration of the pleasures experienced by the individual may be lower as well. However, with a qualitative hedonist theory there could also be a flip side to this consideration. If one were to have a health state which prevented them from participating in some or many pleasures of a lower quality, but still allowed them to engage in pleasures of a higher quality (even if they are experiencing a lower intensity or duration of the pleasure) their level of well-being could still be quite high, at least in cases where their health state does not cause a high level of pain. If the individual's health state were such that there was very little pain and they could still engage in pleasures of a higher quality, then there health state could be viewed as increasing their well-being showing that it could actually be better for the individual to be less healthy. If this were the case, then this state of ill health could be valued over being healthy. This suggests that health or in this case ill health can have a positive

[182] While the sources that were consulted for this project do not *specifically* state that pains also have a quality rating I am assuming that they do.

impact on the individual's well-being. The relationship between ill health and well-being need not always be a negative one.[183] However, even in these cases the state of health of the individual only matters insofar as the individual's experiences of pleasures and pains are concerned. Health contributes causally to the overall well-being of the individual, even though it is not a constituent of well-being.

At first glance, on a desire satisfaction theory of well-being the contribution of health will differ depending on whether the individual desires to be in good health. If the individual desires good health, then the health of the individual directly contributes to the overall well-being of the individual. If the individual does not have a desire for good health (not that the individual desires poor health, but that they just do not have desires about their health one way or the other), then on this view it may not look like health contributes to the individual's overall well-being. Many people who are in a state of good health do not often think of health or desire that they are in a state of good health. This is not the case for everyone in good health, since sometimes people in good health do actively desire to be in a state of good health. However, it seems as though many people do not actively desire good health until they are in a state of unhealth. We often do not value our health until our state of health is lower or less than it was before. For example, on average many people do not think of their health until they catch a cold or other illness, but then they desire to feel well again. Once the ailment is gone they will often go back to not being overly concerned about health in

[183] This is a result found in disability studies, which will be discussed in more depth below.

general.[184] Health or states of good health are often taken for granted, and we do not often desire things that we have taken for granted.[185]

On a desire satisfaction theory of well-being it appears as though a desire for good health is required for health to contribute to well-being, but this is not true. Health can have a large impact on whether our desires are satisfied and on what we desire.[186] Sometimes our health states can impact what we long for or desire because the health state has prevented us from doing those things or has put limitations on us. Our health state can change what we desire and value. Ill health can cause an individual to reflect on the desires that they have and have had in the past. Their health state can change their perspective of what matters to them. For example, suppose that a young man is faced with having to have his knee removed and that there are several options available to him. The young man desires to have a full range of physical activities available to him after his surgery, so this desire will influence his choice in procedures. Now imagine that this young man also desires that he have two complete legs as well. Even with the options available to him there is not a surgery that would allow him to satisfy both of these desires, so the young man must choose between his desires. He must

---

[184] Carel, 2013, 243-244.
This may not always be the case. Some ailments might cause an individual to be aware and slightly more health conscious. In cases of prolonged illness the individual may make health a priority and desire not to become ill again. For cases like a cold or flu I would think that once those particular ailments are gone most people would go back to not being overly concerned about health in general.
[185] Carel, 2008, 26 and Svenaeus, 2013, 231-233.
[186] This is not saying that health impacts one's ability to satisfy all desires that contribute to well-being, but it would have an impact on some subset of desires. Health also does not have an impact on the formation of all desires, but health will have an impact on the formation of some desires. I am not arguing that if one is in a state of unhealth they would be unable to satisfy any desires, or that all of their desires will be formed in relation to their health state. I am simply arguing that there will be desires that health impacts, so there will be some degree to which health contributes to and detracts from an individual's well-being.

determine which of the desires he longs for more, so the appropriate surgery is chosen since he cannot change his mind after the surgery is finished. This health state which required the removal of his knee has both put limitations on his desires and shaped which desires he values more. Before the health state the young man most likely took it for granted that he had two complete working legs so that would not have been a desire that he actively had, but he could have still had a desire to do a wide range of physical activities. Once confronted with this health state he developed a desire that he have two complete legs, but after thought he decided that the satisfaction of his original desire for a wide range of physical activities overrode the new desire presented by the health state. The man's health state presented him with two competing desires and he needed to make a choice over which one he valued more. This example demonstrates that one's health state could have a large impact on what one desires and one's ability to satisfy those desires. On a desire satisfaction theory of well-being satisfaction of desires is what determines one's level of well-being. However, a health state that may alter or restrict one's ability to satisfy desires may not be a negative thing. An individual might find their health limiting their desire to do somethings and this can open up opportunities to try things they might not have tried before. They may find that they enjoy these other activities far more than they used to enjoy the pre-health state activities and these new experiences and changes in the individual's values could result in positively impacting on the individual's well-being. Again it is important to note that while the relationship between health and well-being is complex being less healthy need not imply an automatic reduction in well-being, but in some cases merely a change in what or how one measures well-being.

On a fully informed desire satisfaction theory, it could be argued that the *level* of health needed to satisfy one's desires would be included in the facts that the fully informed version of oneself has. If this is the case, then the fully informed version of oneself would desire to have the *level* of health required to satisfy their other desires. On an ideal desire satisfaction theory the ideal version of oneself would also see that good health is most likely required for the satisfaction of at least some other desires, so here too health could be desired by the ideal version of oneself. However, the ideal version of oneself would also know whether some health states would result in a higher level of well-being than other health state or being in good health. This is because the ideal version of oneself would know how the individual's reflection on their health state may alter their values and the types of desires that the individual would end up having.

Objective list theories of well-being look like they would have the most straightforward implications about the relationship between well-being and health. If health is on the list of goods its relationship to well-being is particularly close. But even if it does not make it on to the list of constituents of well-being, health still plays an important role in contributing to an individual's well-being because an individual's health state can affect how well or to what degree he or she possesses the things which are on the list of objective goods.

Suppose there was a list that did not have health on it, but had achievement or friendship on it. An individual's health state can impact what one can achieve. Imagine an individual who aspires to be a veterinarian specialising in the care of exotic animals. This type of career requires a high level of

intelligence and dexterity. Now imagine that this individual is highly intelligent, but as a child suffered from an illness and the treatment for this illness left him with fingers that would spontaneously lock-up and he is unable to use them for varying amounts of time when this happens. To be a veterinarian requires dexterity that he no longer has on a consistent basis and as there is no warning as to when he will be unable to use his hands, so he can no longer become a veterinarian. His health state has barred him from this achievement and many others that require consistent dexterity to achieve them. This may not prevent all achievements, but it does reduce the degree that he can achieve things and the types of achievements that he can have. This does not bar the individual from creating new goals that would be within his ability to achieve, but it can require him to change these goals, or seek out other forms of achievement. As achievement is on the list of objective goods, being unable to possess or limiting one's ability to possess this good would have an impact on the individual's level of well-being.

Now let us consider friendship. The easiest case that one can consider is an instance when someone is in a state of health that requires that they be isolated, such as a state of health that severely reduces the functioning of the individual's immune system. This would be greatly limiting in one's ability to make new friendships and could affect one's ability to maintain their side of current friendships—reducing the individual's well-being, but possibly (hopefully) only for a short time, or maybe periodically throughout her life. This health state would cause a reduced level of well-being for a short time or possibly sporadically over the whole life of the individual. If it is the case that this health state occurred only for a short period of time in the individual's

life, then it may not have much of an impact on the individual's overall level of well-being. However, if this health state occurred at intervals throughout her life, then it could have a lasting impact on the individual's level of well-being.

While the preceding paragraph focused on how an individual's health can impact on their own ability to make new friends or maintain their side of their current friendships it is important to remember that friendships are two sided relationships. The limitations that one individual may experience due to their health may be completely different to the limitations that the partner friend (the other member of the friendship) may experience as a result of the individual's health state. Friendship is one aspect of well-being that can be greatly impacted by social dimension of ill-health. An ill individual may be able to overcome the limitations imposed on them by their health state, but their friend may not. Chronically ill, or seriously ill individuals may no longer be able to maintain some friendships, not because of their own restrictions or limitations, but because their partner friend withdraws for some reason.[187]

Consider an individual who is unable to make friends; maybe they are lacking interpersonal skills because they lack the ability to form the appropriate positive affective attitude to produce or maintain a bond of friendship. The lack of this capability is not classed as a disease or illness, but is included in health on this account. So, this would be a lifelong health state preventing them from making and engaging in friendships. Their health state has in this instance prevented the individual from having friendships or at

[187] Carel, 2008, 50-51.

the very least has severely reduced the degree to which they could possibly have friendships.[188]

Since hybrid theories of well-being are a combination of the other types of theories it looks as though the relationship between well-being and health is more intertwined than when looking at a single theory on its own. First consider a hybrid theory which combines an objective list theory with a hedonist theory. Earlier when discussing hedonist theories and health I argued that not only does health have an impact on how much pain an individual may experience, but it can also have an impact on an individual's experiences of pleasure as well. Health states can affect the duration and intensity of a pleasure and if qualities of pleasure are taken into consideration health states can influence the quality of the pleasures that an individual may have access to. The second aspect of this hybrid theory would be the portion borrowed from objective list theories of wellbeing. During the earlier discussion I argued that, if health were not on the list of objective goods, health states could determine whether an individual possesses a good from the list or to what degree they can possess goods from the list. On this type of theory, well-being requires the possession of objective goods from the list and enjoying or taking pleasure in the possession of those goods. If health can affect whether or to what degree an individual can possess these goods and the intensity and duration (and potentially the quality) to which these goods can be enjoyed or bring pleasure to the individual, then it would seem that the relationship between health and well-being on this theory is twofold.

[188] This is not saying that health has an impact on one's ability to possess any or all of the constituents of well-being, but it could have an impact on to what degree an individual might possess some of the constituents of well-being.

A hybrid theory of well-being which combines a desire satisfaction theory with an objective list theory would have the same twofold result. As argued earlier, health states impact whether some desires can be satisfied and in some cases health states can influence what is desired. This in combination with how health states can affect whether and to what degree one might possess objective goods from the list shows that health is intertwined in this type of hybrid theory in a twofold manner. This type of theory requires that for a good to contribute to an individual's well-being the individual must also desire it. If due to health states a good from the list cannot be possessed by an individual or can only be possessed to a limited degree and that individual desires it, then the individual's health state would have a negative impact on that individual's well-being.

IV –Health and Well-being: QALYs and Disability Studies

The preceding discussion looked at the impact that health can have on well-being. The discussion approached the topic by looking at health and different types of theories of well-being and seeing how the two might interact to determine what the relationship is. The investigation so far has taken the approach that if health were not a constituent of well-being there would still be an interesting and complex relationship between the two. There has been research done on the impact that health has on well-being that cannot be left out of this discussion. However, I wanted to complete this investigation prior to considering this research. I will discuss two different approaches in the research.

I will first discuss Quality Adjusted Life Years (QALYs), which was developed as a means of measuring the impact of different health states on quality of life. This approach attempts to make quantifiable health measures that can be used in other research, like outcome studies or determining how effective a treatment is,[189] and to aid in policy decisions.[190] Then I will discuss disability studies, which aim to look at how chronic illness and disability impact on individuals' overall well-being. The studies are qualitative and relay on the self-report of the individuals in the study. I will argue that both approaches presuppose a particular type of theory of well-being and that health is valuable because of how it contribute to well-being; so the aims of these studies differ from the task that I have focused on here. I think that the relationship between health and well-being complex and the analysis that I have presented so far holds whether health is instrumentally or non-instrumentally valuable.

QALYs are a measure of health that looks at the time that an individual spends in a particular state and adjusts it to accommodate for the reduction of quality and time the health state will cause.[191] This system of measurement is based on the idea that the quality of life and the quantity of life or time can be qualified by using utility calculation.[192] These calculations often involve determining preference between different health states. If the health state has a greater preference rating then it has a higher utility rating.[193] "The utilities assigned to specific states of health can be estimated using a series of

[189] Hausman, 2015, 1-2.
[190] Hausman, 2015, 3-6.
[191] Hausman, 2015, 36.
[192] Prieto and Sacristan, 2003, online.
[193] Prieto and Sacristan, 2003, online.

techniques such as Standard Gamble, Time Trade-Off or Rating Scale, or by some means of pre-scored health state sorting systems (i.e. HUI, EQ-5D)."[194] If we were to use the pre-scored health state sorting systems to calculate QALYs then we already have some presuppositions about which type of theory of well-being is correct. The Health Utilities Index (HUI) uses "preference-based measures of health –related quality of life."[195] QALYs are meant to measure the impact that different health states have on well-being. If we were to use HUI in calculating QALYs there are already some presuppositions about which theory of well-being is correct built into the method of measurement. The ranking system relies on preferences and while I did refer to desire satisfaction theories through this chapter, they are sometimes referred to as preference satisfaction theories of well-being. Hausman argues that a lot of these ranking systems treat "well-being" and "quality of life" as synonymous, which he views as problematic because quality of life is like a snap shot of a moment of one's life; it measures how their life is going right then. However, well-being is more global than that; well-being measure how well an individual's life goes for them.[196]

I think that QALYs can be useful measures for comparing health states, possible treatments, helping in research, or making policies. However, I don't think that they help us to understand the relationship between health and well-being. The scoring systems used in calculating QALYs seem to imply that any health state that is less then healthy only has a negative impact on well-being and I have shown above that there is room for states of unhealth

[194] Prieto and Sacristan, 2003, online.
[195] Hausman, 2015, 47.
[196] Hausman, 2015, 47.

to positively contribute to well-being too. The arguments presented above show that the relationship between health and well-being is complex, but the arguments work whether health is a constituent of well-being or not. If QALYs measure the value of health they do so in an instrumental way, which leaves no room for health being non-instrumentally valuable.

Disability studies use surveys to determine whether there is a difference in the level of well-being between healthy individuals and individuals who are disabled or chronically ill. These studies have found that there two groups report having similar levels of well-being.[197] The well-being that is being measured in these studies are "subjectively measured well-being, or levels of happiness."[198] These studies tend to show that there is "little correlations between objective health and well-being."[199] However, there have been some studies that indicate that there is a reduction of well-being within the first year after an individual is diagnosed with a chronic illness.[200]

These studies can be quite promising particularly when they seems to indicate that we often over exaggerate how bad we think that a health condition will be.[201] However, this can call into question the accuracy of health based sorting systems discussed above. This is because the systems rely on preference ratings of different health conditions and if we have a tendency to over exaggerate how bad we think a health condition will be, then the measures produced by preferences may be not be accurate. These disability studies also seem to suggest that health has less of an impact on our

[197] Carel, 2013, 251.
[198] Carel, 2013, 251.
[199] Carel, 2013, 252.
[200] Carel, 2013, 252.
[201] Carel, 2013, 252.

well-being than we may think. However, these studies also measure well-being in a way that presupposes a hedonist theory of well-being. When outlining the relationship between health and well-being above I did show that poor health need not always negatively impact on well-being, so disability studies do not offer an objection to the analysis that I have provided. Also showing that both healthy and less healthy individuals have similar levels of well-being does not indicate that the relationship between health and well-being is not complex and intertwined; especially since there is some indication that there does seem to be a drop in well-being in the first year after diagnosis. If anything these studies show that the relationship is possibly more complex that one might have originally thought.

V – Conclusion

I have given a general survey of four types of theories of well-being. This survey has explained the main features of these types of theories as well as some common objections. The common objections were included for two reasons. Objections can help one to get a sense of the types of theories as a whole. Second, the objections to hedonist, desire satisfaction, and objective list theories have motivated others to attempt to address objections by combining theories to make hybrid theories.

Once this survey was complete there was a clear idea of how the different types of theories would deal with health. However, I argued that even if health were not a constituent of well-being it has a complex relationship or impact on how well a person's life goes for them and this complex relationship is best explained using the combination theory of health. Health

may not get named as a constituent of well-being, but it has a widespread impact on the measure of an individual's well-being using any of the general types of theories discussed. Health should not be equated with well-being, but it can be closely linked to many aspects of an individual's well-being.

I have included some discussion about using QALYs to measure health. I have shown that the calculation of QALYs requires us to subscribe to a particular type of theory of well-being and that the value of health lies in its contribution to well-being, which is inherently negative. I have shown that the relationship between health and well-being does not work that way and leaves open whether health is instrumentally or non-instrumentally valuable. I have also considered the findings of disability studies. These show that the relationship between ill health and well-being is not always a negative one, but that there is a reduction in well-being in the first year after the diagnosis of a chronic illness. I think that this supports the claim that the relationship between health and well-being is complex. However, disability studies also presuppose a particular theory well-being.

This complex relationship between health and well-being can be used to show why beneficence and nonmaleficence are so important in medicine. If at the base of our duties not to harm and our duties to benefit or help others is a concern for well-being, then the influence that health states have on an individual's well-being can explain why there is a focus on the restoration, promotion, and preservation of health in medicine. We could also use the complex relationship between health and well-being in combination with the specialised knowledge and skills medical professional possess to explain why their obligations of beneficence and nonmaleficence apply so strongly to

healthcare. Medical professionals are uniquely qualified to restore, promote, and preserve health; in turn, health can have a large impact on an individual's well-being, so it seems that one of the best ways that a medical professional can positively affect an individual's well-being is through their health. In restoring, promoting, and preserving health, medical professionals are influencing the health states of their patients—health states which have an impact on the level of that individual's overall well-being.

Autonomy

One of the guiding principles of medical ethics is respect for patient autonomy. Attempts to adhere to this principle have led to many of our informed consent procedures, but what is it to respect patient autonomy and why is autonomy so important? Why do we value autonomy? One answer to the question of why autonomy is important and we value you it is because it contributes to our well-being. On some accounts of well-being autonomy is a constituent of well-being. However, this is not true for all accounts of well-being. This being the case for the purpose of this chapter (and the thesis more generally) I will be leaving this possibility aside. I will be approaching autonomy not through the lens of well-being, but as something that can be investigated independently.

Autonomy is important because we use it for so many things, including denoting moral and political responsibility, assigning certain rights and obligations to people, and determining moral status and how we are allowed to treat people.[202] Autonomy is also important because people value having

[202] I think that this is generally true across cultures, but I think that the level of importance placed on autonomy and self-governance can vary. However, I think that my statement that this is generally true depends on how we define autonomy. If we define autonomy as requiring that people are independent impartial reasoners, then I think that this would only apply to Western more individualistic cultures, where these features are sometimes thought of as ideal. I argue below that I think that this view of autonomy is problematic and would not be empirically informed. On the other hand, if our conceptualisation of autonomy allows for the inclusion of relational concerns in the deliberative process, whether those include collective responsibilities regarding one's position within a particular society, or the wishes, views, and values

the outcomes in their life being the result of the choices that they have made.[203] For these reasons, our theory of autonomy needs to be general enough to include most adults within the scope of individuals who are autonomous, it must be empirically informed to some extent (meaning that it cannot be completely removed from what we know or have discovered about how the human brain works and the types of capabilities that we have), and our theory needs to be capable of doing the work that is required of it: it needs to be theoretically sound and practically applicable.[204] Since we value autonomy and think that it is important enough that we use it for so many things, if our theory of autonomy is only theoretically applicable, then it appears as though the practical uses that we attempt to engage in will fall flat.

In medicine we often turn to informed consent to ensure that we are respecting patient autonomy, but why do we rely so heavily on consent? This chapter will argue that a *valid* informed consent is important and valuable because it is an expression of the individual exercising their autonomy.[205] The feature of the consenting individual that the moral significance of informed consent is latching onto is autonomy of persons. This chapter will begin by looking at the importance of consent and what we are looking for with our informed consent procedures and practices. This will help to identify what is

---

of those close to the individual, I think that my statement is generally true. I think that if we did not believe that an individual could make decisions for themselves or governed their own actions, then it would be difficult for us to hold them responsible for doing something wrong or disregarding their responsibilities to others. However, I do think that the value/importance put on self-governance can vary between cultures and can compete with other things (like duties to their family or society) that they hold valuable.

[203] Scanlon, 1986, 189.

[204] Baumann, 2008, 446.

[205] There are several mitigating factors that can prevent an informed consent from being valid. These include things that can hinder the deliberative processes and instances when the individual may not be autonomous, meaning they may have slipped through the cracks of the competency requirements.

morally significant about informed consent. I will argue that the moral significance of consent lies in the consent being an expression of the consenting individual's personal autonomy. This is then contingent upon an appropriate account of autonomy of persons, so this chapter will then focus on several different accounts of autonomy of persons, identifying similarities and differences that distinguish the theories. It will argue that Richards' theory, or a theory like Richards', is best suited to do the work that we want autonomy to accomplish with regards to informed consent. Using Richards' account of autonomy I will address some difficulties surrounding informed consent. Some issues include power asymmetries in the doctor-patient relationship, and types of knowledge that are deemed valuable or applicable by the norms of medicine, which can result in epistemic injustice. In the first chapter I argued that cancer care uses a shared decision-making model, but this does not mean that both parties have equal power in the relationship, this is related to some of the epistemic issues that were mentioned in chapter two regarding the epistemic gap and norms of medicine. I will also address worries that an individual's health can impair their autonomy. I think that an account of autonomy like Richards can avoid some of these issues because of the way that it has fleshed out the complex capacities constitutive of autonomy.

I – Informed Consent

There are different approaches that one might take when trying to determine the significance of informed consent. One might work from our current informed consent practices and procedures to try to identify what these practices and procedures are trying to latch onto and what is morally

significant about it. This would be to work from our practices backwards to what those practices are focused around. Or, one might start with an investigation into what it is for an action to be an informed consent, what is distinct about an informed consent that other actions or decisions do not have. Grounding the moral significance of an informed consent in the type of action that it is, we could then work forward to discuss how this relates to our current practices. In this chapter I will engage in the first method, arguing that our practices focus around a feature of persons and it is this feature that grounds the moral significance of informed consent. I will then look at Ruth R. Faden and Tom L. Beauchamp's analysis of informed consent, which follows the second method of investigation. I will argue that although Faden and Beauchamp's analysis raises some important distinctions with regards to informed consent and the corresponding policies and practices, they are too quick to disregard some aspects of policy or practice as not morally relevant.

What does it mean to give consent? When an individual gives consent they are giving another permission to act towards them in a certain way. Informed consent carries with it certain obligations, responsibilities, and protections that merely giving permission does not. In medical ethics "informed consent is a legitimacy requirement for certain actions."[206] Giving consent changes how it is appropriate to treat the consenting individual; the consent restructures and legitimizes the rights and obligations of the involved parties, whether the individual is giving consent to another individual or an institution.[207] Giving an informed consent changes the way that responsibility is divided up between parties in the situation. By consenting the individual is

[206] Eyal, 2012, online.
[207] Simmons, 1998, online.

taking on some of the responsibility for the consequences of the consented action. They have agreed to allow something to be done to them and they have been given information about the intended results as well as information regarding possible unintended results that could accompany the treatment or procedure. The individual has agreed to take on some of the responsibility for the consequences by agreeing to undergo the treatment or procedure. This division of responsibility does not absolve the practitioner or institution of responsibility for the consequences of the treatment or procedure. Both parties involved in the informed consent process will share in responsibility.

As an informed consent legitimizes certain actions, when seeking informed consent, we aim to attain informed, voluntary and sufficiently capacitated consent. Methods that we employ to ensure that consents meet this aim involve ensuring that an individual has the information needed to make a decision as to whether they consent or refuse a treatment or procedure. We attempt to ensure that the individual from whom consent is being sought is consenting or refusing voluntarily, and that the individual is the type of individual that can legitimately give this kind of permission or authorization. We often employ competency requirements when determining who is likely unable to give a valid informed consent. Competency requirements are often designed to identify (or *attempt* to identify) features that can be used to include or exclude individuals from giving informed consents. Ideally our competency requirements will ensure that only those people capable of giving a valid consent will be allowed to consent, but sometimes our guidelines will end up not catching all and only those who can give a valid

consent. In these instances an individual who is not competent to give a valid informed consent may give informed consent (that was not valid), or an individual who is competent may be denied the opportunity to consent. These instances are very unfortunate and problematic, but may not be avoidable when we attempt to use general guidelines.[208] The only alternative to general guidelines would be case-by-case assessments, but these may also produce poor results.[209] Our competency requirements attempt to latch on to features of a person that indicate that they are unable to give a valid informed consent.

Some competence requirements might aim to identify individuals who may need to be protected in some way. They aim to protect individuals who likely have not developed certain capacities, as of yet, that would allow them to make appropriate decisions, or to identify features that would inhibit an individual from bearing the responsibilities or obligations that giving an informed consent would entail. For example, competency requirements which indicate an individual must be a certain age to give an informed consent might be protecting individuals from poor choices of youth, or age

[208] Some definitions of competence may be problematic. For instance, the types of features, that a system might require an individual to possess, to be deemed competent are not the right sorts of feature, maybe these features systematically exclude a group from being deemed competent not for lack of possessing some capacities required for decision-making, but for social reasons. An example of this might be during the slave trade an individuals' competence could be determined by something like race due to the social structures at the time. Although, informed consent practices as we identify them today did not exist at the time, but this would be a clear example of a feature that is not relevant to the individual's decision-making capacities and that is socially motivated, being used to determine competency.

[209] The individuals preforming the assessments may vary in the level of strictness, they could be influenced by certain biases that they may or may not be aware of, and they may put more importance on some features over others. These things could result in individuals who may be deemed as competent by some and not others, and the same sort of issue that general guidelines had; that some people who can give valid consent being denied the opportunity to give consent and other people who cannot give a valid consent being allowed to give consent.

may be an indicator of likely abilities to comprehend the consequences of the treatment or procedure being proposed, or they may be at an age where they have not developed their forward thinking skills, or possibly individuals under a particular age group often have inadequate reasoning skills.[210] There may also be competency requirements about the mental health of the individual giving consent; perhaps individuals with *some* types of mental illnesses would not be able to share in the responsibility for the consequences that go along with consent.[211] For instance, if a mental illness prevents an individual from having psychological continuity (the individual may not identify their past self with their current self, or they may believe that they are a younger version of themselves, etc.) or an inability to grasp onto reality.[212] These individuals may not be able to share in the responsibility that goes along with the consent. Competency requirements point out features that prevent individuals from consenting, whether it is because they lack certain capacities or cannot bear the responsibilities acquired by consenting. However, by pointing out these features that prevent one from consenting, we are also acknowledging that there are features of persons that are morally relevant to people consenting. Taking this into consideration I will now look at Faden and Beauchamp's analysis.

In their book *A History and Theory of Informed Consent* Ruth R. Faden and Tom L. Beauchamp begin their analysis of informed consent by first looking at the origin and history of informed consent. After completing the historical aspect

[210] Some of these examples are used as justification for not allowing adolescents to give consent.
[211] There could be some mental illnesses that would prevent individuals from being deemed competent and others that would not.
[212] Richards, 1981, 6-7.

of their analysis, Faden and Beauchamp identify two distinct conceptions of informed consent. According to their analysis informed consent in the first sense is identified as "a special kind of autonomous action: an autonomous authorization by the patient or subject."[213] It is this special kind of autonomous action that makes informed consent in the first sense morally relevant.[214] For the remainder of this chapter I will refer to the first sense of informed consent as the moral sense. The second sense of informed consent relates more to policy. Faden and Beauchamp present it as "'Informed consent' [as being] analysable in terms of rules governing informed consent in public policy and institutional contexts."[215] For the remainder of this chapter I will refer to the second sense of informed consent as the bureaucratic sense. Faden and Beauchamp argue that these two senses of informed consent come apart in distinct ways as the policy and rules governing informed consent practices can vary. They argue that most of the literature available, at the time of publication of their book, dealt with informed consent without teasing out these two senses.

In many theories of informed consent available at the time there were several elements identified as the concept's analytical components and these were often used as conditions in the definition of informed consent.[216] The elements identified are as follows: disclosure, comprehension, voluntariness, competence, and consent[217] (however, not all theories included this last

[213] Faden and Beauchamp, 1986, 274.
[214] Faden and Beauchamp, 1986, 235 and 280.
[215] Faden and Beauchamp, 1986, 274.
[216] Faden and Beauchamp, 1986, 274-275.
[217] Disclosure requires that the patient is given the information that is required for them to give consent. This information would include what will happen in a

element and some theories called it decision instead of consent).[218] An informed consent on these accounts is attained when some number of these elements have been satisfied; which elements and to what degree they have to be satisfied being things that vary between the different theories.

However, Faden and Beauchamp argue that these elements are not suitable for an adequate conceptual analysis because these elements have emerged from institutional or regulatory settings in which policy dictates consent requirements. These elements reflect the legal and institutional practices that they have emerged from, giving prominence to "the special orientations of both medicine and law towards disclosure and responsibility for patients and subjects."[219] Faden and Beauchamp argue that some of the elements that these theories present as necessary conditions for an informed consent show that the theories have conflated the two senses of informed consent. Some of the theories necessary conditions for consent are derived from policy concerns and do not apply to the moral context. They argue that there is nothing about the nature of informed consent that requires that the elements described above are necessary conditions, and that orienting the meaning of informed consent around these non-necessary elements is mistaken.

---

procedure, what would be involved in treatment, possible consequences or side effects.
Comprehension may also be described as understanding, this requires that the individual understands the information that they have been given.
Voluntariness refers to the patient not being coerced, or manipulated into giving consent.
Competence refers to whether the individual is able to give a valid consent. Is the individual able to give consent, do they possess the right features or abilities to give consent. And finally consent refers to the act of authorizing a procedure or treatment.

[218] Faden and Beauchamp, 1986, 274.

[219] Faden and Beauchamp, 1986, 275.

One such element that they discuss is disclosure: they argue that if one were to have the knowledge to give informed consent then there would be no need for disclosure, and if this is the case then disclosure cannot be required for informed consent.[220] One example of this could be an instance in which a physician becomes a patient: the physician already has the knowledge required to make a decision about their medical treatment, so disclosure in this instance would be unnecessary. According to the reasoning here, if there are instances when a certain element is not required in order for some individual to give an informed consent, then that element cannot be a necessary condition of informed consent.

Faden and Beauchamp argue that through the historical analysis of the emergence and development of informed consent that has taken place in their book these two distinct senses of informed consent have emerged simultaneously and are still working in the framework today, however unnoticed the distinction might be. These two conceptions are often referred to together and do work alongside each other; however, there are times in which they come apart and it is in these instances that the distinction is so important. For example, there can be a time when an individual may be barred from giving consent because they do not meet the policy requirements to be seen as capable of consenting, but they are indeed capable of giving a valid consent.

Faden and Beauchamp argue that the relationship between these two senses is important and that informed consent in the moral sense has an impact on or plays a role in how informed consent in the bureaucratic sense is often

[220] Faden and Beauchamp, 1986, 276.

defined. According to Faden and Beauchamp "[m]any definitions of informed consent in policy contexts reflect at least a strong and definite reliance on informed consent in [the moral] sense."[221] However, the two senses can diverge when making policies about informed consent procedures or practices. This is in part because a policy must stipulate specific rules to govern practice that will be applied generically across all patients. This is one of the reasons that informed consent in the bureaucratic sense often stipulates some form of competence restraints, while informed consent in the moral sense does not. The goal of informed consent policy is to develop a set of rules or requirements that will ideally capture all informed consents in the moral sense, but ensure that it does not include 'consents' that would not meet the conditions for giving an informed consent in the moral sense, meaning excluding those 'consents' that are not autonomously given.[222]

According to Faden and Beauchamp, informed consent is a special kind of autonomous action. It is an autonomous authorization, so it is important to be able to pin point what it is that makes an action autonomous. According to Faden and Beauchamp's analysis of autonomous actions there are three conditions that must be met for an action to be autonomous. For an action to be autonomous the individual must act intentionally, with understanding, and without controlling influences.[223] In the case of informed consent there is one further condition, and that is authorization.[224] Faden and Beauchamp argue that understanding and controlling influences can be placed on a broad continuum, but this is not true of intention since either the individual intends

[221] Faden and Beauchamp, 1986, 284.
[222] Faden and Beauchamp, 1986, 284-285.
[223] Faden and Beauchamp, 1986, 238.
[224] Faden and Beauchamp, 1986, 278.

to do some action or they do not. The continuum described for understanding ranges from complete ignorance to full understanding, which seems appropriate. However, their description for the continuum for controlling influences is a bit vague. The description of things that could land someone closer to the completely controlled end of the continuum includes things like coercion and manipulation, but the other end of the continuum remains unclear. If being completely noncontrolled requires that the individual is independent, detached, and impartial, then this could be difficult to obtain and potentially problematic. The completely noncontrolled end of the continuum would fall to the objections that we do not make decisions in a vacuum free from our relationships with others.[225] Faden and Beauchamp do not give much description on what the noncontrolled end of the continuum is meant to look like aside from being free of controlling influences, but these are legitimate worries.

Since understanding and controlling influence can be placed on a broad continuum any particular action can range from fully autonomous, meaning that the action is fully understood and completely noncontrolled, to fully nonautonomous, meaning that the individual is fully ignorant and completely controlled. Fully autonomous actions may be viewed as actions that are ideally autonomous and as such might not be attainable or very rarely attainable by some small group of people. Because of this, Faden and Beauchamp advocate that we should be more concerned with the section of

[225] Stoljar, 2018, online.

the scale which would account for those actions that are substantially autonomous. [226]

An individual's action may fail to be autonomous because it has failed to adequately meet one of these conditions. For instance, an individual may be fully ignorant, but intentionally act completely free from any controlling influences. According to Faden and Beauchamp, if an action fails to meet one condition then it is nonautonomous, but if it meets the conditions the degree to which the action is autonomous depends on where on the continuum of understanding and controlling influences the individual's action lies.[227] Faden and Beauchamp argue that it is only those actions that fall under the category 'substantially autonomous' that should count as qualifying to be informed consent.[228] They argue that to make informed consent hinge on fully or completely autonomous decision-making "strips informed consent of any meaningful place in the practical world."[229]

Through the historical analysis presented in their book Faden and Beauchamp argue that informed consent requirements did not come about in hopes of giving people the opportunity to make *more* autonomous decisions about their healthcare than the autonomous decisions that people make in other areas of their life. Informed consent requirements came about because of the concern that people were *less* able to act autonomously in their role as patients or research subjects than in other areas of their life. "Assuming comparable capacity for decision-making, one's appreciation of information

[226] Faden and Beauchamp, 1986, 238-239.
[227] Faden and Beauchamp, 1986, 240.
[228] Faden and Beauchamp, 1986, 238.
[229] Faden and Beauchamp, 1986, 240.

and independence from controlling influences in the informed consent setting need not outstrip one's information and independence in making financial investments, hiring a building contractor, or accepting a job offer."[230] If, as they claim, fully autonomous actions occur so rarely in the real world, then it would seem that in many areas of one's life less than fully autonomous actions are common and accepted as adequate for decision-making. The goal is that decisions made in these other areas of one's life are substantially autonomous. Admittedly, the requirements for an action to be seen as substantially autonomous may differ depending on the context of the action or decision.[231] What might be substantially autonomous decision-making with regards to a healthy diet might not require as much information in order to be substantially informed as a decision about which type of knee replacement surgery one should undergo.

Faden and Beauchamp argue that some of the commonly referred to elements of informed consent—disclosure, comprehension, voluntariness, competence, and consent—are not required for an informed consent in the moral sense to be obtained. Faden and Beauchamp illustrate this with their argument against disclosure and say that similar arguments can be made for the other elements as well. However, while working within their conceptual analysis of the moral sense of informed consent, they have worked voluntariness into the analysis using their condition of being free from controlling influences, and comprehension is included in the condition of substantial understanding. They have also managed to include the fifth element, consent, into their conditions through the required authorisation condition. The only element

[230] Faden and Beauchamp, 1986, 240-241.
[231] Faden and Beauchamp, 1986, 241.

that they do not address directly is competence, but they manage to side step addressing this element through the insistence that since an informed consent is a special kind of autonomous action there is no need to consider accounts of autonomous persons.

I think that Faden and Beauchamp do not give adequate attention to competence and what it is our competence requirements are trying to achieve. Competence requirements aim to identify who can give an informed consent. We try to pick out features of persons that would exclude them for being able to give an informed consent. The focus of competence is on features of the person. I think that when we are trying to determine who can give an informed consent we are focusing on the right aspect about consent. When one gives informed consent for a treatment or a procedure we are acting on the person, we are giving them medication or performing a test or other procedure on their body. As the person is the object that is being acted upon, I think that the focus of informed consent should be on the person, and not merely on the act of giving an informed consent. When an informed consent is given, the consent-giver has given the professional or institution permission or authorized them to treat the consent-giver in a certain way. To focus only on choices neglects this special feature that persons have. Autonomy of persons is the feature that we are attempting to pin down when we are thinking about who can give consent.

I agree with Faden and Beauchamp that there are two senses of informed consent, the morally significant sense and the bureaucratic sense. As Faden and Beauchamp argued, these senses developed alongside one another and both senses feed into our current practices and procedures. However, I

disagree that the reason that informed consent in the moral sense is morally significant is that it is a kind of autonomous action. Instead, informed consent in the moral sense is morally significant because it is the expression of an individual exercising their personal autonomy. The moral significance is attached to the individual's personal autonomy, not the type of action that is being undertaken when giving a valid informed consent or refusal. There are external factors that can prevent an individual from expressing their autonomy, such as, control, manipulation, or deficiency in information, which can lead us to think that the significance lies in the action. However, this is misplaced because the moral significance should be attached to the internal feature of persons—their personal autonomy—which the action, in this case a valid informed consent, is an expression of.

I think the distinction between informed consent in the morally significant sense and informed consent in the bureaucratic sense is important because they can come apart and there will always be difficulties when we are attempting to make guidelines that are generically applied across diverse populations. However, when looking at our current practices it seems as though what is central to how we make these guidelines is to look at the persons we are seeking consent from and determine whether they can give this kind of consent. As autonomy of persons is an internal feature, policy requires some sort of guidelines which can be applied across large diverse groups of individuals and that can be externally assessed. This can result in some individuals who should qualify to give informed consent as being grouped with those individuals who cannot, and vice versa. However, this is a difficulty that policies and guidelines face in many areas.

Having concluded this investigation into the significance of informed consent and our current practices I will now present several different theories of autonomy of persons. I will highlight some of the similarities and differences between the different types of theories presented. I will look at some of the common objections to these different types of theories and how they might be addressed, ultimately favouring an account similar to David A.J. Richards' account of autonomy of persons.[232]

II – Accounts of Autonomy

The common element between different theories of autonomy is that they all refer to the self-governance of the individual. Beyond that common ground, there are several ways of looking at autonomy. Some approaches argue that autonomy is a property of actions or decisions, while others argue that autonomy is a property of persons. I will be focusing on accounts which argue that autonomy is a property of persons. At the beginning of this chapter I outlined reasons why autonomy is important and how we use autonomy. Many of the things that we use autonomy for hold the individual at the centre of the consideration. When determining moral status we are determining the moral status of a person or individual. When assigning rights, obligations, and responsibility these also fall on the individual. This is also true when we are determining how we are allowed to treat people. If we use autonomy to do all of these things, then it would seem as though autonomy would properly be described as a property of persons. We don't hold a choice or action responsible, but instead we hold the individual who made the choice or carried out the action responsible. To hold autonomy as a

[232] Richards, 1981.

property of a choice or action looks as though the things we use autonomy for do not have traction. If the things we use autonomy for grip onto the person, then it would seem as though autonomy should be a property of that thing (the person) that these uses grip onto. For these reasons, I will be looking at theories of personal autonomy.[233]

Different conceptions of autonomy will make different claims about what is required for an individual to count as self-governing. Some theories of autonomy will use the same elements for determining who counts as autonomous, but will differ on how much of a role a particular element or characteristic will play in making that determination, or in the process of exercising one's autonomy. The categorization of differing theories of autonomy can be a tricky task.

Some aim to group different theories of autonomy into two separate categories: individualistic theories of autonomy, and relational theories of autonomy.[234] This method of categorisation classifies theories which have developed out of the "atomistic" concept of the person, seeing the individual "as ideally self-sufficient, as operating in a vacuum unaffected by social relationships, or as an abstract reasoner stripped of distorting influences such as emotions"[235] as individualistic theories, while those theories that take into consideration that people are social creatures who bear relations to others are grouped under the heading of relational theories of autonomy. However, this method of categorisation does not appear to be fine grained enough to

[233] This does not mean that there is no reason to have a theory of autonomous action. There could be uses for these theories, but I think that they might be useful alongside a theory of personal autonomy.
[234] Chrisman, 2015, online.
[235] Stoljar, 2014, online.

accommodate the differing accounts of autonomy. It appears to pit any theory of autonomy that takes into account an individual's personal history and social relations against theories that focus on individualism and rational independence.[236] There are many competing approaches to how one takes into consideration people's social relations and personal histories when integrating them into a theory of autonomy. The mere acknowledgement of these social relations in an individual's autonomous decisions or actions, does not fully appreciate the differences in this supposed class of theories.

I think the best way to categorise different theories of autonomy is to pick out some core aspect that they have in common. Ben Colburn does this in his book *Autonomy and Liberalism*. He divides theories into three groups: theories which endorse a certain structure to one's motivations in order to indicate self-governance or autonomy[237]; those that emphasise reason and rational behaviour as core to self-governance or what it is to be autonomous[238]; and theories which hold individuality or 'self-creation' at the core of what it is to be self-governing or autonomous.[239] It is important to note that the theories discussed below hold that there are degrees of autonomy. An individual is not either autonomous or not, and that the individual can be more or less autonomous at different times throughout their life.

---

[236] Above I argued that a theory of autonomy must be empirically informed, meaning that it cannot be completely removed from things that we know and have discovered about how the brain works and human psychology. The requirements in these types of highly individualistic theories don't really line up with the empirical evidence that we have about how we think and reason.
[237] Colburn, 2010, 9.
[238] Colburn, 2010, 8.
[239] Colburn, 2010, 12.

II.I – Motivations

This group of theories take self-governance to require that our motivations adhere to a certain structure for them to count as self-governing or autonomous.[240] The structure that is required often has two levels; there are first-order desires, and some higher-order endorsement of the first-order desire. On these types of theories there is a hierarchical structure to one's motivations. An individual will have a first-order desire (or preference) concerning some action, and the individual will also have higher-order desires (or preferences) which have first-order desires (or preferences) as their object; a desire (or preference) for which first-order desires (or preferences) the individual wants to have.[241] These theories do not require that the individual always or actually reflect on their first-order desires, but they do require that if the individual were to reflect on their first-order desire they would in fact desire or have a preference in favour of or endorse that particular first-order desire.

These types of theories have developed out of a theory of persons put forward by Harry G. Frankfurt. Frankfurt argued that defining persons as a collection of corporeal characteristics and states of consciousness is not adequate, as it can be equally applied to animals "which are manifestly not persons in any normal sense of the word."[242] According to Frankfurt this broader application of the term 'person' to other animals does significant harm, and cannot be viewed as merely a verbal offense, because it diminishes philosophical vocabulary and increases the possibility that we might

[240] Colburn, 2010, 9.
[241] Colburn, 2010, 9.
[242] Frankfurt, 1971, 5.

overlook important areas of inquiry when doing philosophical work about persons. Frankfurt wrote that:

> [T]he criteria for being a person do not serve primarily to distinguish the members of our own species from members of other species. Rather, they are designed to capture those attributes which are the subject of our most humane concern with ourselves and the source of what we regard as most important and most problematical in our lives.[243]

With this is mind, Frankfurt argues that there is one essential difference between persons and other animals. This essential difference is the structure of a person's will. Humans have the capacity to form what Frankfurt called 'second-order desires'. A second-order desire is a desire to be moved by certain preferences or desires. All animals, both those that are persons and those that are not, have 'first-order desires: they want to do *X* or they do not want to do *Y*, and these desires motivate their actions throughout their lives. Frankfurt argues that, "[n]o animal other than man, however, appears to have the capacity for reflective self-evaluation that is manifested in the formation of second-order desires."[244] This is the capacity that, Frankfurt argues, should be used when we are determining to which entities to apply the term 'persons'.

However, Frankfurt makes a distinction between two different types of second-order desires. If an individual were to simply want to have a certain desire, then they would have a second-order desire. If an individual were to

[243] Frankfurt, 1971, 6.
[244] Frankfurt, 1971, 7.

want a certain desire to be their will, meaning that the individual wants the desire to move them effectively to act, then this type of second-order desire is a second-order volition.[245] Frankfurt argues that second-order volitions are essential to being a person, not merely having second-order desires. It is only second-order volitions that contribute to the structure of the will that differentiates persons from non-persons.

One might wonder if Frankfurt has forgotten some important aspect which is usually highlighted in some way when thinking about 'persons'. Rationality has been pointed to as being something that we often think of when trying to carve out perimeters for using and applying 'person'. However, on Frankfurt's account rationality still plays an important role. It is only through one's rational capacities that one is capable of being critically aware of one's own will and forming second-order volitions. Rationality is required for one to exercise one's capacity for reflective self-evaluation. "The structure of a person's will presupposes, accordingly, that he is a rational being."[246]

Following Frankfurt, Gerald Dworkin puts forward a theory that would fall under this categorisation. When Dworkin first developed this view of autonomy there were two conditions that he claimed were required for autonomy: authenticity, and procedural independence. Authenticity requires that an individual's higher-order desire endorses or approves of the first-order desire that is motivating their action, and that they identify with said desire. For an individual to identify with their desire is simply for the

[245] Frankfurt, 1971, 10.
[246] Frankfurt, 1971, 12.

individual to acknowledge that, or have the feeling that, "this is my desire".[247] Dworkin does not spend a great deal of time giving a full explanation of procedural independence. The explanation given is short but relatively straightforward, and it relates to what Frankfurt described as being the distinguishing characteristic of persons. Procedural independence requires that the individual can critically reflect on their first-order desires and determine whether they endorse or reject those desires motivating actions.[248] For an individual to be autonomous there cannot be external influences that hinder their ability for the critical reflection that is required for procedural independence to take place.

According to Dworkin's view, an individual is autonomous when their higher-order desires approve or endorse their first-order desires. So, an individual could have a desire to do *x* and this desire would motivate an action (the action of doing whatever it is that is indicated by *x*); for the individual to be autonomous in doing *x,* they would need to have a higher-order desire about their desire to do *x* and for the higher-order desire to be formed in a manner that adheres to procedural independence. For the individual to be autonomous the higher-order desire must be one of approval or endorsement in favour of possessing that desire and it motivating their actions. Let's say that an individual is going on vacation to an area with typhoid fever and thinks it would be best to get a vaccination for typhoid fever before they go. The action in this case would be getting the vaccination. For this action to be autonomous, according to this view, the individual would need to have a higher-order desire endorsing the decision to get the

[247] Dworkin, 1981, 211.
[248] Dworkin, 1981, 212.

typhoid fever vaccination. In this instance, the individual would be acting autonomously. An example of a non-autonomous action on this account could be demonstrated with an individual on a diet. The individual is trying to lose weight by avoiding cakes. However, the individual has a first-order desire to eat a slice of double fudge cake with chocolate icing, but the individual does not approve of this desire; they have a higher-order desire that they should stick to their diet and not eat the cake. The individual ends up eating the cake and on this account the act of eating the cake was non-autonomous.

In *The Theory and Practice of Autonomy* Dworkin presents the entirety of his original theory of autonomy, in doing this he highlights some of the objections to his theory and difficulties that the theory encountered. This being the case, while writing his book, Dworkin rejects the authenticity condition, arguing that this condition is mistaken. Dworkin found that having the authenticity condition as a requirement for autonomy had some unacceptable implications.[249] Dworkin argued that all that is really needed for autonomy is procedural independence. Through procedural independence an individual can critically evaluate their first-order desires, which motivate them to act, and work to change those motivations if they so desire.[250] Autonomy does not consist only in critical reflection, but also includes what the individual will do with their reflections and evaluations of their first-order desires. The ability for critical self-reflection can help the individual to motivate a change in their first-order preferences and desires.[251] However,

[249] Dworkin, 1988, 15.
[250] Dworkin, 1988, 16.
[251] Dworkin, 1988, 17.

these changes may be constrained by outside factors that do not reflect the internal critical self-reflection and evaluation of first-order desires. Sometimes one's ability to act is restricted by what it is possible for them to do and this in turn will determine what they will do.

One aspect of this view that I think gives it some extra strength over some other theories is that on Dworkin's account an individual can make an autonomous choice to allow others to make decisions for them. This choice could be made in an instance when the individual does not think that they are particularly apt to make the decision on their own. [252] For instance, if an individual were to ask their physician to make important decisions with regards to their treatment, it could still be an autonomous choice. The choice to allow others to dictate decisions in our life could occur for reasons other than an individual believing that they are not qualified to make the best decision in a given situation; this choice can be made on a more global level as well. Dworkin uses the example of a soldier to explain this point. Being a soldier puts limitations on what an individual can autonomously choose: it's restrictive in how one can live and the types of past-times one might participate in, and the schedule is highly regimented and controlled. However, according to Dworkin the soldier is still autonomous because they have a higher-order desire that approves of the desire to be a soldier and in being a soldier the person autonomously chooses to adhere to the limitations that come with being a soldier.

Objections to this type of theory include worries about an infinite regress. If we need higher-order desires or preferences to endorse our first-order

[252] Dworkin, 1988, 19.

desires, why not require some even higher-order desire or preference to endorse the other higher-order preference? Some argue that there needs to be some explanation as to what makes one level of endorsement the end point over another.[253] Frankfurt mentioned this objection in his paper, but thought that it was not too much of a worry. If an individual were to be critically self-reflective about their critical self-reflections it would be fine; the important thing was that they were being critically self-reflective about which desires or preferences were motivating their actions and if they approved or rejected those desires as motivating factors of their actions. Higher-order desires are arrived at through critical self-reflection, while first-order desires can be about anything and do not require much thought in their formation.

Another objection raised is that if a first-order desire and a higher-order desire do not line up, why is it that we should change our first-order desire to be in line with our higher-order desire: what gives our higher-order desires prominence over our first-order desires?[254] This objection is one of the reasons that Dworkin later argued that the authenticity condition is mistaken.[255] Dworkin argued that if we were to take the authenticity condition out of the requirements for autonomy this objection would no long apply to his account, since there would no longer be a requirement that the individual's higher-order desires endorse their first-order desires. This approach neatly side-steps this objection because if there is no need for endorsement then

[253] Dworkin, 1988,19. Dworkin mentions this objection himself. He does provide a reference to three people for introducing two objections. I decided to use this source because it includes both the objection and the proposed solution.
[254] Colburn, 2010, 11
[255] Dworkin, 1988, 17. In this source Dworkin outlines how the earlier version of the theory included the authenticity principle, which he decided was no longer needed.

there is no need to explain why one level of desires would have prominence over the other.

A broad theory, such as Dworkin's, has merits because it can be applied so generally. This theory would allow for a large number of individuals to be included in the group of autonomous individuals. However, this theory would also be hard to apply. Dworkin argues that his theory has the strength of not being elitist, in that those individuals who count as autonomous are not only intellectuals and philosophy professors.[256] To be autonomous one does not need to sit around and engage in critical self-reflection all the time, and one does not need to even think too much about it. Dworkin argues that:

> [A] farmer living in an isolated rural community, with minimal education, may without being aware of it be conducting his life in ways which indicate that he has shaped and moulded his life according to reflective procedures. This will be shown not by what he says about his thoughts, but in what he tries to change in his life, what he criticizes about others, the satisfaction he manifests (or fails to) in his work family and community.[257]

However, this is not saying that everyone is autonomous. Even on such a broad account there will still be people who are non-autonomous. But, taking Dworkin's claim into consideration, we may not be able to tell who is autonomous. Dworkin argues that you can see that a person is autonomous by looking at the way they live and you need not know much about their thought processes, or even require that they tell you of their thoughts.

---

[256] Dworkin, 1988, 17.
[257] Dworkin, 1988, 17.

According to Dworkin, an individual may not even be aware that they are conducting their life based on reflective procedures. However, I would have to wonder whether it would be possible to be unaware that you are engaging in critically self-reflection and evaluation. Someone might be able to reflect on something and not be aware of it, but critical self-reflection and evaluation requires some attention be paid to the process. It's not only a matter of reflection, but requires critical self-reflection, which is a more active practice. Whether it would be possible to engage in critical self-reflection without being aware that you are doing it or not, Dworkin's suggestion makes it really difficult for us to determine who is autonomous—especially if a person can meet the conditions for being autonomous while being completely unaware of it. It would seem as though Dworkin's theory is so broad that it would not be very useful when we are trying to determine whether an individual is autonomous, and whether they can give an informed consent.

II.II – Reason and Rationality

This group of theories conceive of practical reasoning or rational self-legislation as core to what it is to be self-governing or autonomous. One theory that would fall into this group of theories is put forward by David A.J. Richards.

Richards draws from Frankfurt in claiming that a defining characteristic of persons is that they can critically self-reflect on their desires and make choices with regards to which desires to endorse and reject, shaping their lives in response to this critical self-refection. However, unlike Dworkin, Richards does not see this critical self-reflection as the root of autonomy, nor does

Richards have any mention of different levels of desires in his account, so he departs from Frankfurt as well. Richards argues that autonomy "is a complex assumption about capabilities, developed or undeveloped, of person, which enables them to develop, want to act on, and act on higher-order plans of action which takes as their self-critical object one's life and the way it is lived."[258] For Richards, in order for an individual to be critically self-reflective they must be autonomous. It is through the possession and use of capabilities that are constitutive of autonomy that one is able to be critically self-reflective of their desires in order to choose to act and make life plans.[259] According to Richards, it is these self-criticisms resulting from critical self-reflection that explain one's self-regarding emotions, such as, pride, shame, guilt, self-respect, regret, or one's sense of self integrity.[260]

Richards argues that the capacities required for autonomy are complex, but one way to approach understanding such complex capacities is to look for examples of what form the absence of these capacities might take. This leads to a categorization presented by Stanley Benn indicating that such absences can be identified as defects in epistemic rationality, or practical rationality, "or of psychic continuity whether as believer or agent."[261] Defects in epistemic rationality include those things which make an individual's belief immune to arguments or evidence, such as extreme forms of self-deception or paranoid fantasies. Defects in practical rationality would include being unable to act now on the basis of future probable desires. Richards uses the example of a child not conserving water for later thirst, kleptomania, and

[258] Richards, 1981, 6.
[259] Richards, 1981, 7.
[260] Richards, 1981, 6.
[261] Richards, 1981, 6.

other compulsive tendencies. An individual's disassociation from their body or an inability to identify with his or her self as the same person over time indicates a defect in psychic continuity. Richards uses the example of schizophrenic disassociation as a defect in psychic continuity. Richards' examples point to very clear instances of these types of defects, but from the descriptions provided of each of these defects one can give examples that are not as extreme and may simply indicate errors in reasoning, or that the individual is simply poor at reasoning in certain instances. The only defect that seems to be immune from this consideration is the defect in psychic continuity. Having explored examples of what the absences of the complex capacities required for autonomy might look like, Richards moves forwards to identify the complex capacities required for autonomy.

Richards presents a non-exhaustive list of what he labels as "complex" capacities constitutive of autonomy. These capacities include "language and self-consciousness, memory, logical relations, empirical reasoning about beliefs and their validity (intelligence), and the capacity to use normative principles in terms of which plans of action can be assessed, including principles of rational choice in terms of which ends may be more effectively and coherently realized."[262] Notice here that the capacities described as constitutive of autonomy rely heavily on one's rational capacities. Richards argues that it is through these capacities that an individual can call their life their own, and that it is through "self-critically reflecting on and revising, in

[262] Richards, 1981, 7.

terms of arguments and evidence to which rational assent is given, which desires will be pursued and which disowned."[263]

Not only does Richards' account appear to hold rationality as a core element to autonomy, but Richards also argues that the development of the capacities constitutive of autonomy for individual self-definition is central to being a person and is essential to one's self-esteem and integrity.[264] This appears to indicate that rationality and reasoning are core elements of who we are. This is a particularly strong claim to make in passing close to the end of a paper, but the prior arguments presented by Richards might be used to explain this claim. According to Richards, critical self-reflection is important for self-regarding emotions. These self-regarding emotions can play a role in who we are and can have an impact on our self-esteem. Richards argues that in order to engage in critical self-reflection one must be autonomous, or have and use the capacities that are constitutive of autonomy. It would seem to follow from his argument that rationality and reason are elements of who we are, but I do not think that he makes a strong enough argument that they are core elements. There seems to be many things that help to shape us into the people we are and the personalities that we develop. Our use of these capacities plays some role in our development, but whether they are core to our development or just some of the pieces should most likely be addressed elsewhere and would probably involve several studies in psychology.

An objection commonly raised against these types of theories is that they put a limiting role on how desires and preferences contribute to an individual's

[263] Richards, 1981, 7.
[264] Richards, 1981, 7.

autonomous choices. On some theories desires or preferences may be regarded as distracting one from reasoning rationally. For these theories the worry is that people do not or cannot reason impartially when making a decision as prescribed by such a theory.[265] People are influenced by the culture and society they belong to and the many relations that they have with other people. If the requirement of independence is too strict, then individuals would not meet the requirements of being autonomous. It could turn out that no one would end up counting as autonomous.

This is not the case with the theory presented by Richards because according to this theory it is through the capacities required for autonomy that one can critically reflect on one's desires and rationally endorse or reject those desires, thereby taking one's desires into consideration when making autonomous choices. Richards' theory does not require that an individual reason impartially, but that their beliefs can be adjusted if new evidence is presented. We form beliefs throughout our lives and they are influenced by people we meet and the cultures that we participate in. However, this does not mean that the evidence that we gather through our experiences with people and cultures that we might encounter will always serve to support our current beliefs: some of this evidence will challenge those beliefs and as such we can exercise our capacities to determine whether the challenge is sufficient to change those beliefs. So, in a sense Richards' theory of autonomy does not require us to set aside our desires or preferences, or to be impartial in order to

[265] For an individual to reason impartially it would require that the individual reason without considering their desires or preferences in the reasoning process, or when determining what to do.

reason rationally, which means that this theory of autonomy can avoid this objection.

Another concern that is often linked closely with impartiality is that impartiality might require one to distance themselves from their emotions when reasoning. Emotion is often considered to be an influence that reduces one's ability to reason clearly or to make the appropriate rational choice. This does not seem to be the case for Richards' account, or at least with regards to emotions pertaining to the self. According to Richards' account the rational capacities that are constitutive of autonomy are the root of the personal or self-regarding emotions mentioned earlier, meaning that reason and rationality come prior to and explain emotions directed at oneself. In this way this theory does acknowledge these emotions, which could indicate an acknowledgement of their influence on how one chooses to act and make life plans. However, this theory says nothing about other emotions, so this concern may still apply with regards to emotions that are not self-regarding.

One might argue that Richards' account of autonomy is too demanding. In the presentation of his account of autonomy Richard's indicates that there are quite a few capacities that are required for autonomy, and the wording in the presentation of his account indicates that the list provided is not exhaustive. This theory appears to require a lot from an individual's rational capacities for the individual to count as being autonomous. However, Richards does not indicate to what degree one must possess the capacities constitutive of autonomy to be autonomous. Each of the capacities mentioned can be possessed to varying degrees. For instance, an individual may have a poor

memory, a good memory, a great memory, or an eidetic memory.[266] Could the individual with a poor memory end up being just as autonomous as an individual with an eidetic memory, or would the person with an eidetic memory (who possesses the other capacities to some degree) always be more autonomous than the individuals whose memories are not as good? Richards would need to make clear whether there is some sort of threshold for the different capacities that one would need to meet to count as autonomous.

The possibility that this theory might be too demanding cannot be raised as a strong objection to this theory until the degree to which one must possess these capacities is fleshed out. If an individual only needs to possess all of the capacities on the list, then the theory might not be too demanding; but if the individual must be highly proficient or possess these capacities to a high degree, then this theory may be too demanding.

Some of these concerns were mentioned earlier when discussing the examples that were used to illustrate defects which would indicate absences of some or many of the capacities required for autonomy. The defects as described can be used for much more mundane examples, which could simply indicate poor reasoning skills. For example, when considering defects in practical reasoning Richards points to a child who drinks water now while not conserving any for later, kleptomania, and to other compulsive behaviours. However, a less severe example would be instances of instant gratification as opposed to delayed gratification. Many individuals will take an immediate reward over a later reward, even in instances when the later reward is larger.

[266] Eidetic memory is the ability to recall images with vividness, a total recall. Sometimes it is also called a photographic memory.

This would seem to be an instance which would fall under what was described as a defect in practical reasoning, but at the same time it simply looks like an instance of poor reasoning. We wouldn't want to say that just because the individual took a smaller immediate reward instead of waiting for a larger reward that they are not autonomous, or that this poor reasoning means that they have a defect in their reasoning that would preclude them from being autonomous.

Richards uses extreme forms of self-deception and paranoid fantasies as examples of defects in epistemic rationality, but there can be less dramatic cases that would fit with the description of defects in epistemic rationality. There can be instances when individuals hold onto beliefs that they value even in the face of evidence contrary to certain aspects of those beliefs, or that might suggest that their beliefs are somewhat lacking in support. These might be instances of faith instead of being a defect in epistemic rationality. This is not an instance of poor reasoning, but it is an instance of using the descriptions of defects which would indicate an absence of the capacities that are constitutive of autonomy, in a less extreme example which may result in an individual satisfying the description for a defect in practical rationality or epistemic rationality even though we would think that they are still autonomous. If we are to take these defects as seriously as one might be led to believe by the severity of the examples provided, then it would seem that demonstrating a defect in these areas (even if it is only an instance of poor reasoning) might lead one to be deemed as not autonomous. This can have some debilitating effects for the individuals so named. Looking at the extreme examples that Richards gives can be used to highlight capacities that we

would warrant as important to autonomy, but the descriptions used to define the defects that these examples are supposed to illustrate can apply to activities or behaviours which are not indicative of lacking the capacities constitutive of autonomy.

II.III – Individuality

This type of theory emphasises an individual's creation of their life or life plan. The individual "is a (part) author of their own life."[267] This type of theory prioritizes the individual as a designer of their own destiny (at least to some degree), viewing autonomy as a global property.[268] What Colburn means by this will be addressed below. Individuals plan and engage in their lives through a succession of decisions that will hopefully create a coherent life plan. However, this does not limit someone from changing their mind about their path or introducing a new goal. A change such as this would be the result of the individual working towards some goal and through their experiences and for reasons resulting from the work that they were doing the individual comes to a new goal or wishes to change the direction that their life is moving in. This (part) authorship is what is referred to, by Colburn, as the individuality of the person in question, and individuality is how the

[267] Joseph Raz as quoted in Colburn, 2010, 12.
[268] It can be noted that the definition of individuality is almost identical to autonomy. The use of individuality is meant to be a description about how we should understand the notion of self-governance, which is at the core of autonomy. Colburn is making a claim about what it required for individuality and by extension to live an autonomous life. I think that he attempts to tease out his theory this way because he argues that autonomy is a global property, it is concerned with whole lives, while local instances that meet the requirements of individuality can be viewed as contributing to the global property or autonomy. There needs to be some way to connect what people do in their day-to-day lives to this thing (autonomy) that is meant to apply to the life as a whole.

notion of self-governance should be understood.[269] It is a combination of the individual's desires, wishes, values, goals, and preferences that influence how the individual seeks to design or shape their life.[270]

Colburn puts forward a theory that falls into this category. Colburn's view is global, focusing on the life of the individual as a whole. For autonomy to be a global property means that it cannot be determined by individual instances, but that it can only be viewed by looking at the life of the individual, or by focusing on the life plan.[271] It is the coherence of this plan and the individual's decisions that determine whether they are autonomous. On this account, the individual decides for him- or herself what defines a valuable life. The values which guide an autonomous life are determined by the individual's own views on what it is important to do and what will make their life go well for them.[272] Colburn argues that an individual does not decide (or is not required to decide) what is valuable from a position of complete detachment; rather, they can make these decisions from a position of attachment.[273] When deciding whether something is valuable which would result in making a new commitment to something, there is a sense in which the individual is deciding on the value of that thing from a position of detachment because it is

---

[269] Colburn, 2010, 12 & 19.
Highlighting that a person is a part author of their life makes room for things that happen in their life being out of their control. Authors have complete control of the stories that they create, but in life we are often confronted with unexpected twists that we need to adjust to. We might plan our lives to take a specific route, but these routes can be changed for many different reasons. The inclusion of (part) in front of author does complicate the task that Colburn has set out to accomplish, but I think that Colburn attempts to make up for this unpredictability with his Endorsement and Independence conditions. He also wants to be able to say that someone can alter their life plan without that shift interfering with the coherence of their life plan that would result in their life not being autonomous.
[270] Colburn, 2010, 22-25.
[271] Colburn, 2010, 21.
[272] Colburn, 2010, 22.
[273] Colburn, 2010, 23.

new. However, an individual can also reaffirm the value of something and since they are already committed to the value of that thing the position that they are occupying with regards to that value is one of attachment. On Colburn's account the individual can reaffirm or renounce the value from this attached position by reflection and assessment of their current commitment.[274]

Colburn argues that a life can be more or less autonomous depending on whether the individual throughout their adult life decides what is valuable for their self and whether the individual's decisions at any particular time meet two conditions.

> *Endorsement*: She has a disposition such that if she reflects (or were to reflect) upon what putative values she ought to pursue in her life, she judges (or would judge) of some such things that they are valuable
>
> *Independence*: She is in a state where her reflection is, or would be if it took place, free from factors undermining her independence.[275]

According to Colburn the Endorsement condition is not overly demanding since it requires only that *if* an individual were to consciously reflect on their values they would indeed endorse them. The Endorsement condition does not require the individual to actually consciously reflect on their values and commitments. Colburn argues that endorsement of one's values and commitments can be explicitly chosen, through reflective contemplation, or the endorsement can be implicit. The implicit endorsement of a value or

[274] Colburn, 2010, 23.
[275] Colburn, 2010, 25.

commitment can be demonstrated on the individual's part through their actions.

Colburn goes into more detail concerning the Independence condition. In order for an individual to meet the independence condition she must be "free from factors which undermine the extent to which we can say that she is deciding for herself."[276] There are constraints that would cause an individual not to meet this condition aside from manipulation and coercion. If an individual were to come to value something due to manipulation the Independence condition is not met, even in an instance where the individual would have decided that thing were valuable had the individual been given evidence that was free from manipulation. If the individual's views about the choices available to them are influenced by mechanisms that the individual cannot be aware of, decisions made as a result of their perceived options do not meet the Independence condition.[277] In instances where an individual values something for reasons other than their belief that the thing is indeed valuable, the value or commitment is made for 'content-insensitive reasons' and will not meet the Independence condition.[278] For instance, if an individual were to value a certain activity, but only because someone they cared about valued it, the individual's commitment to that activity would not meet the Independence condition because if the person the individual cares about were to value something else the individual would not value that

[276] Colburn, 2010, 26.
[277] Colburn makes this claim, but gives very little explanation as to what is meant by this. He seems to think that there may only be some instances when an individual's choices might be influenced by mechanisms that they cannot be aware of and that in these instances their decisions would not meet the Independence condition. Below I argue that this can be problematic.
[278] Colburn, 2010, 27.

activity. So, the individual's commitment to that activity would not contribute to their autonomy, and their valuing that activity is only instrumental. The value that they are really committed to in this instance is that whichever activity makes the person they care for happy, and the individual is only committed to the activity because of this other value. Had the person the individual cares for valued another activity, then the individual would have been committed to that other activity. This is why the commitment to the activity is 'content insensitive'.[279] It would appear as though the commitment to making the person one cares for happy can influence the value that you assign to doing some activity that you neither like nor dislike, in such a way that valuing that activity does not meet the Independence condition.

Colburn elaborates on some of the ways that coercion can hinder an individual from meeting the Independence condition. Colburn discusses how repeated coercion can cause an individual to disvalue options that they would have otherwise valued. Coercion in relationships of dominance can undermine an individual's independence. This is because the values that the individual endorses due to this coercion are rooted in the dominant individual's (the coercer's) will and they are not the result of the individual endorsing those values or commitments. However, Colburn argues that there can be instances of coercion that can threaten an individual's autonomy without undermining the Independence condition. The example used is that of being mugged. The common trait in all of the cases outlined above is that the individual's commitments or values are removed from their control.

[279] Colburn, 2010, 27.

Colburn views autonomy as global, meaning that its focus is on the autonomous life of an individual. Since the focus is on the life of the individual this means that it is not just concerned with the individual's decisions about what is valuable, but with their actions as well. Living an autonomous life requires more than meeting the Endorsement and Independence condition: it requires that our life takes shape in the way we have decided is valuable. An autonomous life is one that is self-directed. What it means for a life to be self-directed, for Colburn, is that an individual's life goes a certain way because they have made it or shaped it to go that way, and this means that the individual must bear the consequences that result from the way that they choose to live.

However, when presenting the theory and giving examples of instances that meet the Endorsement and Independence conditions, Colburn points to individual instances of choices and actions that are autonomous. Colburn also gives an example of an individual choosing to undergo a religious conversion based on new commitments the individual has to what is valuable, thus changing what would have appeared to be a coherent life plan to something possibly very different. However, Colburn argues that if the decision to make this conversion satisfied the Endorsement and Independence conditions, then the individual has autonomously chosen a new life path. This seems to imply that the individual decisions and choices that go into the making or designing of the life plan can each be autonomous, so this theory is not global in the sense that Colburn tries to describe. If autonomy is global in the way that Colburn claims, then each decision, commitment, or value would not need to meet the Endorsement and Independence conditions because autonomy

would be determined over the whole adult life of the individual. Colburn does not want individual instances to count as autonomous, only the life of the individual or the life plan. However, it would be very hard to try to apply the Endorsement and Independence conditions to the life or life plan of the individual. The way the conditions are designed requires that they are applied (or could be applied if the individual were to reflect on their values) to individual instances.

Colburn states that if an individual's views about the choices that are available to them are influenced by mechanisms that the individual cannot be aware of, decisions made as a result of these perceived options do not meet the Independence condition. Though Colburn makes this claim, he gives very little explanation as to what is meant by this. If it means that, if the individual's values are influenced by factors that they might not or cannot be aware of, and the presence of *any* influence like this would result in a failure to meet the Independence condition, then it seems unlikely that there are many autonomous choices. We are often influenced by factors that we are unaware of, such as keen advertising strategies[280], implicit biases[281][282], cognitive dissonance[283], and fundamental and self-serving attribution error.[285]

---

[280] These strategies might include subliminal messaging or different types of propaganda.
[281] Implicit bias is when our decisions and values are influenced by biases that we are unaware of.
[282] "Implicit Bias," Kirwan Institute for the Study of Race and Ethnicity, The Ohio State University Accessed November 1st 2015 http://kirwaninstitute.osu.edu/research/understanding-implicit-bias/
[283] Cognitive Dissonance when your beliefs about the value of something are inconsistent with an action that you've performed causing dissonance, then you must do something to accommodate for this, this can also occur at times when we try really hard to get something and this effort makes the thing appear better than it actually is. For example, when individuals rush a sorority or a fraternity, or if there were difficulties with an application for a university and the individual had to put extra effort into sorting these difficulties out, they may choose to attend that university if

These are a few ways that our views might be influenced by mechanisms that we are unaware of. However, if Colburn meant that there may be some subset of factors that might influence the individual's views about the options available to them, then he should give examples of these influences and why they would result in the decision failing to meet the Independence conditions, while influences such as the ones listed above may not.

III – Synthesis

All of the theories presented above associate critical self-reflection about one's desires or values as being important to autonomy. Dworkin and Colburn base autonomy on critical self-reflections that meet the right conditions. One of the right conditions, and the only required condition for Dworkin, is that of independence. For one's critical self-reflections to be autonomous these reflections must be done in a way that is independent or free from factors that would undermine the independence of the reflective process. In contrast, Richards argues that autonomy is required for one to be critically self-reflective about his or her desires or values. For one to critically reflect in this manner they must have the capacities that will allow for critical self-reflection and these capacities are constitutive of autonomy.

In this observation Richards is correct: there must be some set of faculties or capacities that one must possess in order to engage in critical self-reflection.

---

accepted, even if that university was not their first choice. https://web.mst.edu/~psyworld/cognitive_dissonance.htm

[285] This type of attribution error is the result of the tendency for individuals to assign blame for their personal failures to external factors but in instances when others fail in the same way we are likely to assign blame to internal factors. For example, if an individual does poorly on a test they might blame the wording of the questions, but if their friend also does poorly the individual may blame their friend for not studying hard enough. Philips and Gully, 2013, 182.

Moreover, the list of these capacities provided by Richards seems to be correct. By focusing on the capacities that would make it possible for one to be self-reflective Richards avoids any worries about endorsement (or authenticity) principles which Dworkin encountered and Colburn may still encounter.

For Richards' theory or a theory like it to be applicable there is more work to be done. For instance, more needs to be said about how the capacities constitutive of autonomy need to be utilised. The capacities on Richards' list are developed over time. As we grow we tend to gradually develop these capacities and become more and more proficient at exercising them as time goes by. If mere possession of these capacities were all that is required to count as autonomous, then this would mean that once an individual can be said to have developed each of these capacities they are autonomous. However, this seems counterintuitive since one can first develop some of these capacities without having a grasp on what it means. For instance, self-consciousness would require that an individual have some sort of concept of themselves as themselves. Using studies like the mirror or mark test, psychologists suggest that we have the concept of 'me' at about the age of two.[287] However, the capacity for self-consciousness seems to imply more than recognition that you are you. Self-consciousness involves a higher awareness of oneself than mere recognition and this takes longer to develop. Another example of how self-consciousness develops gradually is revealed by looking at aspects of the self, such as an individual's gender identity. Studies suggest that an individual's gender identity is rather fluid in early

[287] Bertenthal and Fischer, 1978, 44-45.

childhood, meaning that a child may identify as one gender or another depending on the situation that they find themselves in. This often occurs until about the age of six when the child begins to identify with a particular gender consistently.[288] This gradual development is true of the other capacities mentioned on the list provided by Richards.

Mere possession of the capacities constitutive of autonomy is not enough to be autonomous, so some level of proficiency is required. However, we must be careful to not set this bar too high. When determining how proficient one must be at exercising these capacities we must also take into account that we typically have deficiencies in our reasoning. When presenting Richards account I cautioned about poor reasoning. We can perform well in certain types of reasoning within a laboratory setting, but in real life our performance of these same skills can be poor. We have a tendency to fall victim to biases or fallacious reasoning. We might be good at understanding statistics or odds, but when we attempt to apply those same principles to our lives they fall flat.[289] When evaluating our own failure with another's failure we typically attribute our own failure to external factors, while we attribute their failure to internal factors. So if we fail we may attribute it to the wording of an exam or the conditions in the room, while the other person didn't study hard enough.[290] We also have a tendency to take a smaller immediate reward rather than waiting for a larger reward. These things all seem to show that we aren't particularly good at utilizing our decision-making skills. This being the case we would want to avoid setting the proficiency requirement too high. It

[288] Martin and Ruble, 2004, 68-69.
[289] Crities and Kodish, 2012, 403.
[290] Sherman, 2014, online.

could be that to determine to what proficiency one must be capable of exercising these capacities, once they have been developed, we might turn to studies in developmental psychology for assistance.

IV –Autonomy and Health

Using an account of autonomy like Richards we can look at how autonomy can be impacted by health, or more specifically chronic illnesses like cancer.[291] An individual's health state can have an impact on how well they exercise some of the complex capacities constitutive of autonomy. When an individual finds themselves faced with a serious diagnosis like cancer they can be confronted with a complex mix of emotions, and will be confronted with a large amount of information with the expectation for making decisions regarding their medical care. Undergoing such an ordeal can change the individual in ways that they may not have wanted to be changed in. Because of these changes some might wonder if the ideal of autonomy has a place in medicine. I think that for these types of challenges to hold traction depends on how autonomy is defined. If autonomy is defined in a way that requires a person to be an independent, detached, impartial reasoner, then illness would most certainly challenge this ideal. I have argued above autonomy does not need to require that kind of a reasoner and the types of theories outlined in this chapter do not require that. The kinds of dependencies that can develop due to illness do not need to result in a loss of autonomy on the ill person's part and I think that Richards' account of autonomy can accommodate this.

[291] Above I noted that people can be more or less autonomous at varying times in their life. While something like a cold or flu may impact on an individual's ability to exercise their autonomy for a short time the influence of the illness on autonomy typically subsides rather quickly. In the case of chronic illnesses that have a longer duration the impact that health can have on autonomy can be quite different.

Richards' account leaves room for the relationships and the contexts that we develop in. There is no claim that one must reason in a vacuum, detached for relationships, culture, or social group that contributes to forming desires and motivates one's choices. However, this isn't to say that the *current* ideal endorsed by the norms of medicine isn't referring to the independent, detached, impartial reasoner.[292] There is quite a bit of literature that agrees that this needs to change.

I think that a theory like Richards can accommodate for the kinds of changes that individuals experience in ill-health and would avoid some of the challenges made to the ideal of autonomy. In chapter one I gave some preliminary remarks about what I think would be required for the combination theory of health to be a complete theory. I said that the account of illness that would be incorporated into the combination theory would be a phenomenological account of illness. That statement will be important for this discussion. Phenomenological accounts of illness highlight that ill-health can have an impact on the individual's personal identity.[293] The change to a person's identity and relationship to their body can be profound. This can cause problems for some accounts of autonomy, but I think that an account like Richards will not face these same types of problems. Richards' account can accommodate changes in beliefs and ends, there is room for self-regarding emotions, which are involved in changes of self-identity. Richards argues that the complex capacities constitutive to autonomy are integral in creating who we are as a person and developing our self-esteem and

[292] Carel and Kidd, 2017, 338.
[293] Carel, 2013, 247-248.

integrity. This being the case I think that this type of theory can be paired with a phenomenological account of illness.

An individual's health can have an impact on how well they can exercise the complex capacities that are constitutive of autonomy. The sheer amount of information that the individual receives after a cancer diagnosis can be difficult to cope with and remember. Even if an individual has a good memory they may have difficulty keeping all of the important facts together, so this is one capacity that their health can impact on. A lot of information can also make it difficult for them to use empirical reasoning about their beliefs or normative principles of rational choice to determine which ends may be efficiently and coherently realized. However, stating that something can be difficult to use does not mean that they cannot use it at all, just that they may be less proficient than they normally would. They may be temporarily less autonomous, or require more time to go through and make a decision. In cancer care they use a shared decision-making model in the hopes of reducing the effects of information overload and to take some of the pressure of the decision-making process. If this model were to work ideally, then it could really help patients to cope with some of these proficiency reducing issues. Below I will discuss epistemic injustice and how that can cause difficulties both for the informed consent process and autonomy more generally.

V –Epistemic Injustice and Autonomy

In the first chapter I argued that our theory of health influences medicine; the types of treatments that get included, how research is approached, and how

we train professionals. The theory of health I proposed, while I did stipulate that I would likely use a naturalistic account of disease, was not entirely dependent on the biomedical sciences. Then in chapter two when discussing the knowledge and skills of medical professionals I touched on the norms of medicine currently giving biomedical sciences epistemic priority. This results in narrowing the view of what types of things count as knowledge and understanding, meaning that some ways of knowing and understanding fall out of the dialogue; like the kinds of knowing and understanding derived from the experiences of the patient.[294] This results in an epistemic gap between medical professionals and patients.

In cancer care they use a shared decision-making model; the aim of which is to encourage an active dialogue with participation between the patient and the medical professionals addressing the patient's care and to help patients to give an informed consent. However, since there is this epistemic gap achieving the aim of the shared decision-making model may be quite difficult and the resulting epistemic injustice generate problems for patient autonomy. The patient can suffer two types of epistemic injustice: testimonial injustice and hermeneutical injustice. I will address these in turn.[295]

A testimonial injustice occurs when a speaker's epistemic trustworthiness (credibility) is judged by the hearer to be at a deficit because of prejudices or stereotypes that the hearer holds regarding the speaker's group membership,

[294] Carel and Kidd, 2017, 337.

[295] I think that it can be difficult to order which of these two types of epistemic injustice to address first because I think that they are linked in a way that is hard to tease out. Part of the credibility deficit that patients experience through testimonial injustice has to do with the type of knowledge that they have being the type of knowledge deemed appropriate to contribute to the hermeneutical resources of the discipline. So in some sense part of the reason they are viewed as less credible is the result of their hermeneutical marginalization.

(in this case being ill).[296] Credibility here is directly linked to one's credibility as a knower or a giver of knowledge. In the realm of medicine the types of knowing that count as knowledge play a role in how a speaker is perceived as a knower. A heavy reliance on biomedical sciences influences what types of knowledge are given priority and how we go about attaining knowledge with in medicine; more weight is given to knowledge gained through the methods and results of biomedical sciences. The credibility of a speaker, as a knower, in a medical setting is partly influenced by relationship to the type of knowledge that is deemed appropriate by the disciplinary norms of medicine. This results in an asymmetrical distribution of power and credibility between medical professionals and patients. Couple this with negative stereotypes of illness within our society and the ill person is vulnerable to both testimonial and hermeneutical injustice.

Some of the prevalent stereotypes of ill persons within our society speak directly to the ill person's epistemic abilities.

> The ill are often stereotyped as, *inter alia*, cognitively impaired, overwrought, unable to 'think straight', existentially unstable, anxious, morbid, and so on, due to their condition or their psychological response to it.[297]

These stereotypes are contrary to the ideal of autonomy and the characteristics required for autonomy in medicine; namely that the individual be a rational, objective, detached, independent reasoners.[298] And because the

[296] Fricker, 2007, 27-28.
[297] Carel and Kidd, 2017, 338.
[298] Carel and Kidd, 2017, 388.

type of knowledge and understanding that the ill person has of their condition vary from the types of knowledge medical professionals view as pertinent to the medical condition in question. The patient's testimony can be viewed as lacking in relevance and failing to contribute epistemically to the medical dialogue.[299] After such encounters the patient can feel as though they are not being heard by their physician, or that their concerns are not being met. This can leave both members of the dialogue feeling frustrated and can put strain on the shared decision-making model.

This tension between patients and medical professionals can be exacerbated by the power asymmetries within medicine. The ideals of what types of things count as knowledge within the field gives epistemic authority to medical professionals, who have the requisite in depth knowledge backed by the biomedical sciences that is favoured, and this can limits patients ability to exercise their autonomy. If their concerns are not being viewed as relevant or are not being addressed appropriately in the proposed treatment options, then the patient does not have the requisite knowledge they need to exercise their autonomy appropriately. The do not have the empirical resources needed to assess their beliefs, or the information required to make judgements about which ends may be effectively and coherently realized.

This problem arises from the knowledge and understanding that they possess about their condition is not being included in the hermeneutical resources of the field. The privilege given to the biomedical sciences within the norms of medicine preclude the type of knowledge that the patient has about their health state from being include in the hermeneutical resources of medicine

[299] Carel and Kidd, 2017, 337.

because the knowledge is not of a certain kind, namely not found through the methods, or derived from the results, of biomedical science. Ill persons are being hermeneutically marginalised because they have an unequal role in shaping our understanding of some important experience, in this case being ill.[300] The ill person is unable to communicate their experiences in a way that gains purchase within the social understandings of medicine, and in some instances society as a whole. The hermeneutical resources, the network of social meanings and concepts, available to the ill person are not adequate for them to make sense of their experiences and prevent those experiences from being communicated to others within medicine, or society, in a way that they can be understood.[301] This results in hermeneutical injustice, which is defined by Miranda Fricker as: "the injustice of having some significant area of one's social experience obscured form collective understanding owing to hermeneutical marginalization."[302]

These kinds of epistemic injustice harm the patients, but they also cause problems for the aim and intent of the shared decision-making model. The shared decision-making model is meant to help patients give an informed consent, but patients are disadvantaged in their position within the doctor patient relationship. The unequal power relations in the doctor patient relationship hamper the participation of the patient in the fruitful dialogue that is required for the shared decision-making model to reach its intended aim. The inability of the patients to effectively communicate their experience due to a lack of shared hermeneutical resources contributes to this problem.

---

[300] Fricker, 2007, 152-153.
[301] Fricker, 2007, 147-148.
[302] Fricker, 2006, 102.

Effectively reducing their ability to exercise their autonomy and adding to the harms that they experience from epistemic injustices. If the patient's ability to exercise their autonomy is reduced in these ways it is particularly worrisome because the moral significance of informed consent lies in the consent being an expression of the individual exercising their autonomy.

Adopting a theory of health that is phenomenologically informed will alter the types of knowledge that are viewed a pertinent to medicine. The inclusion of the ways of knowing and understanding illness that the patient has into the types of knowledge applicable to medicine will help reduce the hermeneutical marginalization experienced by ill persons. This can also help medicine to move away from the ideal of autonomy that characterizes the autonomous individual as an independent, detached, impartial reasoner. Between the inclusion of different types of knowledge and moving away from the current ideal of autonomy we can reduce the epistemic injustices experienced by patients.

VI – Conclusion

In this chapter I have argued that the moral significance of informed consent lies in the consent being an expression of the individual exercising their personal autonomy, and not in the act of consenting being an autonomous action of a special sort, namely an autonomous authorization. Faden and Beauchamp put the moral significance of informed consent in the wrong place; they place the moral significance on the act instead of on the person. I argue that through looking at our informed consent procedures we can see that the competency requirements are trying to pick out features of persons

that will indicate that they are able to take on the shared responsibility that giving an informed consent places on both parties. I think that the focus on picking out these features says something important about what we are trying to do with informed consent. Faden and Beauchamp were too quick to dismiss competency in their analysis of the moral significance of informed consent.

I then outlined several different types of theories of personal autonomy. I argued that while Dworkin's theory is broad enough to allow an individual, who determines that someone else is better able to make decisions for them, and remain autonomous, but I think that his theory is too broad and difficult to apply. Colburn's theory of autonomy has a similar starting point as Dworkin's, but there can be some strong objections raised against his theory, which I don't think that the theory can address in its present state. I argued in favour of Richards' theory of autonomy. I think that having a theory of autonomy that requires a set of complex capacities constitutive of autonomy is on the right track. A theory like this can explain how people become autonomous over time, and it can be supported by evidence produced in psychology. In the introduction to this chapter I argued that a theory of autonomy should be theoretically and practically applicable. A theory like Richards' has the benefit of mapping onto psychology well; meaning that it can have some explanatory power. It is also the type of theory that can be adjusted if findings provide appropriate evidence to do so.

Richards' theory of autonomy also has the benefit of picking out the types of capacities that our competency requirements identify as being important for giving an informed consent. The types of capacities identified by this theory

are also the types of capacities that we could develop methods of measuring. This gives Richards' theory an advantage over the other theories because with the appropriate means of measurement we could definitively determine who could give an informed consent on an individual basis. However, as this cannot be done for each individual undergoing medical treatment, because it would be time consuming and labour intensive, generalised guidelines are the most efficient way to judge competency requirements in practice. This is not to say that this theory of autonomy would not be helpful for creating those guidelines. Identifying the capacities that are constitutive for autonomy can help us to make better guidelines for policy purposes; showing that this theory not only works theoretically, but is also practically useful.

I have also discussed the relationship between autonomy and health. I think that Richards' account of autonomy can avoid some of the challenges that health can have for autonomy, especially challenges regarding self-identity. When an individual develops a chronic illness, like cancer, they can face changes in how they view or identify themselves and their relationship with their body. I have explained how they changes can be accommodated using Richards' account of autonomy. In previous chapters I flagged up the shared decision-making model used in cancer care and some epistemic worries that can be found in medicine. I argue that patients can experience testimonial and hermeneutical injustice and discuss how this can impact on their ability to exercise their autonomy and the impact that these injustices have on fulfilling the aims and intent of the shared decision-making model. I argue that if our theory of health is phenomenologically informed we can reduce the epistemic injustices experienced by ill persons and that it would better fit with the

intent of the shared decision-making model. It would also discourage the use highly individualistic ideal of autonomy that is currently held within the norms of medicine.

End of Life

Death is inevitable. For some of us it will come sooner than for others. When it does come, our death can go more or less well for us.[303] Our death is something that most of us accept intellectually. We know that all living things must die and that this will apply to us eventually, but we do not often speak of death.[304] In our society today it is easier to put off thinking about our death because we often separate ourselves from death; people who are dying are often relegated to specific wards in the hospital, [305] hospices, or sections in retirement homes where residents who require more care reside, which are often kept out of mind and out of sight from the rest of society. The topic of death is often taboo or impolite to bring up in conversation.[307] This can make it difficult to address issues surrounding death and to properly think about and express ourselves about our death.

There are several stages of cancer and when we cannot treat cancer with the aim of curing the patient, the patient is said to be terminally ill. In what follows I will be discussing palliative care and much of this discussion is not specific to cancer, but is general to terminal illness. When one is terminally ill their health deteriorates more and more until they die. The combination

---

[303] Scarre, 2012, 1082.
[304] Ismael, Accessed 23/09/2015, 1.
[305] Thomasma, 1997, 7-8.
This is directly mentioned from the source. These wards may be the intensive care unit or wards that specialize in palliative care.
[307] Ismael, Accessed 23/09/2015, 1.

theory of health can capture some of these nuances well. The deterioration of the individual's health is often characterized with more than the progression of the disease. It is true that the disease progresses, but this progression is also marked by the gradual loss of the capabilities included in the combination theory of health. The phenomenological experiences of terminal illness can also help us to work towards ways of helping terminal patients' deaths go well for them. Palliative care like any other form of medical care or treatment can be taken up or refused by the patient. Palliative care offers treatment for symptoms and a large range of other services, and patients can choose to accept all of these, some, or none. I think that if they accept even minimal portions of what is covered under palliative care, then they are receiving palliative care and that their dying process can go more or less well for them. In this chapter there is little discussion of patients who refuse palliative care, but I think that what is said about a 'good death' would still apply. The discussion that follows is about what would make a death go well for an individual, not what treatments or methods of care are needed to accommodate that.

This chapter is going to look at what would make our death go well for us; what makes for a good death?[308] There can be several answers to the question: what makes for a good death? These answers can take several different approaches. One approach would be to say that a Good Death is one that comes at the end of a Good Life, and is then influenced by what we think that a Good Life entails. However, this answer comes at the question from a

[308] 'Good death' is terminology frequently used within the literature. Since many supporters of palliative care typically argue that with good palliative care there is no need to have assisted-dying as an option, it would seem likely that they do not associate this terminology with it being the direct translation of *euthanasia*.

different direction than the one taken in this chapter. This approach is evaluating the goodness of a particular death as an evaluation of the end of a life. A Good Death in this sense is a measure of what we had in life, what we left behind, and possibly how we touched other lives along the way. The dying process on this view is only a small portion of the evaluation taking place. An individual on this view can have a Good Death, but the death, as in the process to becoming dead, did not go so well for the individual. Only some people will be able to achieve a Good Death in this sense, and rightly so, not everyone has a good life. This kind of view doesn't give us much guidance on how to help the death go well for the person whose death it is. The conceptions of a 'good death' that will be addressed in this chapter are ones that are referring to dying, the process which one goes through to arrive at death, and as such a 'good death' is one that goes well for the person whose death it is.

I will argue that a 'good death' is one that promotes the dying individual's well-being as much as possible and respects her autonomy for as long as possible. To do this I will first look at a view of what makes for a good death that is *recognised* by professionals working within hospice and palliative care. This view receives a lot of support in the academic literature—both concerning palliative and hospice care and when discussing a 'good death' in general. This being the case, the standard view is shown in the literature to be a statement about what makes for a good death, not what makes for a good death in a certain context, like medicine or palliative care.[309] According to this

[309] The sources consulted for this chapter included authors working in medical ethics and philosophy of death. If the sources were not so varied there may be some support for the claim that this conception of a 'good death' was meant to be context

view, a good death requires that one is self-aware and aware that one is dying; that one participates in the planning of one's end of life care; that one is surrounded by family and loved ones; and that one is as free as possible from pain, suffering, and distress.[310] I will refer to this view as the 'standard view' and I will argue that it is incorrect for several reasons. Most importantly, it has counterintuitive implications because it limits the people who can achieve a 'good death' to only those individuals who are terminally ill, or whose health can be shown to be in a steady and persistent decline, they have entered into the dying process. Only those individuals with a prolonged dying process will be capable of achieving a 'good death', those individuals who grow old and remain relatively healthy until they die will not achieve such a death. Somehow these individuals' deaths cannot go well for them. The counterintuitive aspect is not that it limits who can achieve a 'good death', but who is excluded, and that one must go through an extended dying process. However, if asked some people would indicate that a 'good death' would be one that occurs in old age in one's sleep.[311] This is only one way that the accepted view of a 'good death' produces counterintuitive results. In this chapter I will provide further arguments showing that the standard view is incorrect. I will argue that the real standard for a 'good death' is whether the manner of death promotes the person's well-being and autonomy.

---

dependent, but due to the variation in sources I think that it is safe to assume that the view put forward was not intended to apply to only medical contexts.

[310] The features of the standard view being important for a good death is not confined to medical professionals and academia, some of these features in varying degrees can be found in popular conceptions of a good death. However, being recognised by medical professionals and appearing in the academic literature justifies my calling the view 'The standard view'.

[311] Kim and Lee, 2003, 626. While the sample size in this study is small it does provide evidence that some people do hold this view.

A large portion of this chapter will present arguments and discussion from within a palliative care setting. The definition of palliative care that is used in this chapter and put forward by WHO explicitly states that palliative care does not hasten death. However, when discussing end of life care it is important to also include some discussion of assisted dying, so this will be addressed later in the chapter. The conception of a good death that I argue for in this chapter is compatible with assisted dying, so it works equally well within the palliative care framework or in places that allow for assisted dying.

I – The Standard View

The standard view is a stance on what makes a death go well for the person whose death it is. This view has been found both in the literature on palliative and hospice care, but also is a view put forward outside of the context of medicine. While there is not one defined 'standard view' in the literature I have identified these features as being consistently present, as such, a criticism of these features would not be misplace. If a view is lacking one or some of these feature(s), then it may escape any criticisms made to the missing feature(s). To introduce the standard view I will begin by looking at the literature about a 'good death', then use some studies to illustrate that this conception of a 'good death' influences how palliative and hospice care practitioners approach patient care. The studies will demonstrate that even if practitioners do not explicitly refer to these criteria as required for a good death, their approach to their patients and their practice reflect the influences of these criteria. The standard view that is reflected in practice today was taken up in the 1960's when Cicely Saunders started the hospice movement.

Saunders thought that there was a better way to help patients through the dying process than the methods practiced at the time and these thoughts motivated her to open St. Christopher's in 1967.[312] Now "the hospice movement for better palliative care has spread round the world … to over 145 countries."[313] The ideas that Saunders put forward motivated a change in practice and these ideas can still be seen today in our current hospice and palliative care practices, although possibly with some adjustments to accommodate changes in technology.

There is an idea of a 'good death' that is argued for in the literature. The list of criteria for a 'good death' include: (1) self-awareness;[314] (2) the absence, as much as possible of pain, suffering and distress;[315] (3) the presence of family and loved ones;[316] and (4) involvement in planning their end of life care and treatment.[317] Self-awareness is a two-part criterion because it requires that the individual be self-aware in the sense that they are (1a) conscious and cognitively present[318] and also that (1b) the individual is aware that they have entered into the final stage of their life. In other words, they must be aware that they are dying (this criterion often includes some reference to a level of acceptance of their dying).[320] The second criterion requires an absence, as

---

[312] The Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care September 24th 2015 Research Group Seminar
[313] https://www.nottingham.ac.uk/research/groups/ncare/events/seminar-24-sept-2015.aspx Accessed December 31st 2018.
[314] Scarre, 2012, 1082-1083, Thmasma, 1997, 9-10, Schenck and Roscoe, 2009, 64-66; Mak and Clinton, 1999, 101.
[315] Thomasma, 1997, 13-14. Schenck and Roscoe, 2009, 65. Mak and Clinton, 1999, 100.
[316] Miller, 1995, 93. Mak and Clinton, 1999, 103-104. Woods, 2005, 251-252.
[317] Thomasma, 1997, 10-11. Schenck and Roscoe, 2009, 61-62 & 65. Miller, 1995, 93. Mak and Clinton, 1999, 102-103. Woods, 2005, 246-247.
[318] Scarre, 2012, 1082-1086 and Randy and Verheijde, 2012, 510-512.
[320] Mak and Clinton, 1999, 98. Authors such as Geoffery Scarre (2012, 1082) have argued that a good death is not possible because the two identified requirements of a

much as possible, from pain, suffering, and distress. This includes physical, psychological, and emotional pain and distress, so it does not focus only on the type of pain that can be managed through medication.[321] There is often an emphasis on maintaining strong personal relationships at the end of one's life, so (3) the presence of family and loved ones is included in the criteria for a 'good death'.[322] Finally consider the fourth criterion for a 'good death', the patient's involvement in planning and treatment for their end of life care. This can include things like advance directives, which specify when treatments should be withdrawn or withheld, and can also include things like assigning a medical power of attorney in the event that the patient is no longer able to make medical decisions.[323] Some also include, in this criterion, the patient's preferences about where they would like to die; recent research suggests that in the UK 70% of people would like to die at home but that 50% of people die in hospital.[324] This would show that at least some of the people who would prefer to die at home are not doing so.

---

good death, namely awareness that one is dying and acceptance, produce a contradictory set.

[321] This criterion seems plausible, but later in this chapter I will explain why it might not be.

[322] Almost every paper that has been read for this chapter has made some reference to the importance of family and loved ones being around the patient during the dying process. Some papers have discussed the difficulties that some family members may have if the patient's preferences for treatment or refusal of treatment differ from the family members' own views about what their family member needs. Other papers have stressed the importance of the patient having the opportunity to strengthen their personal relationships with family and loved ones. Other papers have indicated the need that some patients might have for closure through seeking forgiveness or making a confession. This can be important for the patient's sense of completion with regards to ending of their life. There are many different reasons given for the importance of having family and loved ones around while dying; each has their benefits and disadvantages.

[323] Thomasma, 1997, 8.

[324] Dying Matters, Accessed November 15th 2015 http://dyingmatters.org/page/frequently-asked-questions

Some of these criteria may be interpreted as being more relevant now than they may previously have been, due to the types of medical and technological advances that have been made. Today we have a tendency to live longer than individuals who lived in different times, we recover from diseases at a better rate due to advances in treatments, and we can prolong the biological functions of the body in hope of giving it longer to heal. There are many things that we can do now with technology to prolong life, or stave off death for just a little longer.[325] However, with these advances in technology and medical science come other concerns about death, such as how far we should go to prolong life: if giving a patient more time results in more intense or prolonged suffering, should we prolong their life at all costs? We have treatments now that can reduce the symptoms and discomfort of a condition, but cannot cure the condition. In these cases the patient is terminally ill, but can still continue on without really knowing that they are dying because they are being treated and can continue engaging in their normal daily activities.

In his paper "Ensuring a Good Death" David Thomasma gives an example of a young woman who has an inoperable abdominal tumour.[326] Over the course of several months, after three or four shunts and antibiotic therapy successfully help her to live a decent life, the patient later experienced intense pain and suffering. The patient was dying from the time that the tumour was classed as inoperable; she just didn't really understand because she was offered treatment that gave her more time at a decent life.[327] The advancements in technology and medical science allowed this woman to

[325] Thomasma, 1997, 7-8.
[326] Thomasma, 1997, 10.
[327] Thomasma, 1997, 10.

have more time, but the interventions provided to her resulted in an ever growing tumour and a very painful death. We can prolong life, but we cannot prevent death; death is still an inevitability, and our mortality is a fact.

These advancements in technology and medical science have inspired academics working in these areas to look more closely at death and the patients involved, helping them to arrive at the standard view of a 'good death'. However, this view has had an impact outside of academic journals and discussions. The standard view was also part of the motivation behind the hospice movement. The theory and experiences of Cicely Saunders, founder of St. Christopher's Hospice, are still at the root of palliative and hospice care today.[328] The standard view of a 'good death' is reflected in the World Health Organisation's definition of palliative care. The World Health Organization defines palliative care as:

> [A]n approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:
>
> - Provides relief from pain and other distressing symptoms;
> - Affirms life and regards dying as a normal process;
> - Intends neither to hasten or postpone death;
> - Integrates the psychological and spiritual aspects of patient care;

[328] Mino and Lert, 2005, 229. Mino and Lert based this paper on the results of several different qualitative studies conducted in France.

- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.[329]

This definition of palliative care makes no specific reference to helping patients to achieve a good death nor does it make direct reference to the criteria for a 'good death' as such. However, we can see the criteria for a 'good death' mirrored in the aims or description of what palliative care is and how it is supposed to function or be facilitated. This definition directly addresses (2) the pain, suffering and distress criterion. Palliative care provides support of many kinds, to both the patient and their family. One might argue that by offering this support palliative care recognises the importance of close personal relationships (3) during the dying process and at the end of the patient's life. By regarding dying as a normal process the

[329] World Health Organisation s.v. "Palliative Care."

definition may be referring to how palliative care workers should approach dying and how they should encourage their patients to cope with their own deaths. If "regarding death as a normal process" refers to how workers are to aid their patients and their families in coping with the patient's death, then it would coincide with the criterion (1b) awareness that they are dying. For a patient to regard their dying as a normal process they would need to be aware that they are dying, and this awareness is one of the criteria (1b) for a good death, but if all this requires is that the patient regard dying as a normal process in general, then the patient need not be aware that they are dying. However, at least part of the (1) awareness criterion is highlighted in this definition without referring to (1b) the patient being aware that they are dying. Helping patients to live as actively as possible is directly related to (1a) the patient being conscious and cognitively present because being conscious and cognitively present is required for living actively.

In addition to being expressed in the aims of palliative care, these criteria are internalised by and influence practitioners working in the field. Those working in the field may not explicitly endorse these criteria as being important for a 'good death', but you can see these criteria influencing their views about what is important for patients and how they approach patient care. Practitioners often report that it is important for patients' circumstances to meet these criteria whether the practitioner regards these criteria as helping the patient to die well or simply that it is important for patient care. There has been a lot of research done concerning palliative care, how effective it is,[330] how best to implement it,[331] how palliative care workers' beliefs

[330] Hughes, 2005, 289-301.

surface in their interaction and treatment of patients,[332] and whether approaches and values in palliative care are culturally independent or influenced by particular religious or cultural beliefs about death and the afterlife,[333] among many other research questions. This research is not limited to medical research, but is as multidisciplinary as the practice itself. I will use three different studies to show that these criteria influence palliative care practitioners in their practice and approach to patient care. This supports my claim that the standard view not only occurs in academic literature, but influences and is reflected in practice.

Gert Olthuis and Wim Dekkers conducted a study to look at how palliative care practitioners view well-being and how these views contribute to how they treat their patients. Olthuis and Dekkers interviewed 19 palliative care professionals to determine what is viewed as important for patient care in the palliative care setting.[334] The study found that there were six areas or features which were most commonly cited by palliative care professionals as being indicative of good patient care and important for patient well-being and quality of life. These features were: the nature of well-being, emphasising life, trying to meet patient preferences, treating the patient as a person, completing life, and dying well.[335] The findings of this study suggest that the areas or features that palliative care professionals cite as being important for well-being, and the reasons given to justify this importance, often cite the criteria for a 'good death'.

---

[331] Randy and Verheijde, 2012, 510-511.
[332] Olthuis and Dekkers, 2005, 307-337.
[333] Schenck and Roscoe, 2009, 62 & Kim and Lee, 2003, 624-637.
[334] Olthuis and Dekkers, 2005, 308.
[335] Olthuis and Dekkers, 2005, 314-320.

When asked about the nature of well-being, many of the respondents indicated that the well-being of patients must be assessed based on that specific patient; what might promote one patient's well-being may not promote another patient's well-being. The well-being of a patient depends on that patient's illness and how it is affecting that individual. However, the respondents also indicated that many of the above features identified as being important by the study increase or promote the well-being of *all* patients.[336] So while the respondents claim that patient well-being is subjective, they also maintain that the features identified by the study contribute positively to well-being and quality of life for *all* of their patients, which implies some kind of objectivity.

In Olthuis and Dekkers' study a feature of palliative care that was indicated as important for patient well-being is the emphasis on life. "A number of participants emphasised the fact that palliative care is concerned with life rather than death."[337] This emphasis on life promotes patient well-being by trying to focus on addressing pain and symptom management in order to allow or help the patient to continue participation in life until they die. This is mirrored in the description of palliative care given by the World Health Organisation. However, when discussing the emphasis on life several respondents expressed concerns about how good palliative care will end up prolonging life, to some degree, and whether this extra time allows patients to live better.[338] As stated in the definition of palliative care, the aim of palliative care is to improve the quality of life of the patient, but neither to

[336] Olthuis and Dekkers, 2005, 315.
[337] Olthuis and Dekkers, 2005, 315.
[338] Olthuis and Dekkers, 2005, 315.

prolong life nor to hasten death. The concern that good palliative care may prolong life is that the quality of the extra life the patient gains may not help the patient to live better and goes against the definition of palliative care that is endorsed by the world health organisation. The extra time the patient gains may be of a lower quality of life, or extend their experiences of pain or suffering. Emphasis on life relates clearly to the pain, suffering, and distress of the patient, criteria 2 and 1a, as participation in life requires that the patient is conscious and cognitively present.

While more time may be desired by patients, there are questions concerning what types of treatments, particularly life sustaining treatments, might be offered to the patients in a palliative care setting. Shinmi Kim and Yunjung Lee found that many of the acute-care nurses that took part in their study would not accept life sustaining treatments such as artificial nutrition and hydration.[339] However, in their preliminary research they found that those physicians or healthcare professional who would refuse this type of treatment for themselves would recommend it to their patients.[340] These studies appear to indicate that those healthcare professionals who are frequently exposed to hospitals and sick people are likely to choose less aggressive end of life treatment, such as artificial nutrition and hydration, cardiopulmonary resuscitation, and mechanical ventilation.[341] This could indicate that with frequent exposure to these treatments, healthcare professionals may think that they do not add to well-being or a better dying process. The studies also suggested that nurses, who have more continuous exposure with the patients,

[339] Kim and Lee, 2003, 629. This study surveyed 185 nurses.
[340] Kim and Lee, 2003, 627.
[341] Kim and Lee, 2003, 629.

have higher refusal rates than the physicians in the same wards.[342] This is interesting because those who are more frequently exposed to dying patients[343] are not willing to undergo some of the treatments that we offer to patients at the end of their life. These treatments may be suggested to comfort patients, but these treatments do prolong life.

The refusal of those who are continually exposed to these treatments may indicate that they feel that the extended time these treatments offer may be seen as offering patients a low quality of life in their final days or possibly as merely extending the pain and suffering that the patient and their family are experiencing. The high refusal rates of these treatments may hint at a deeper issue with the type of treatments that we are offering to those individuals who want a little more time. There may also be some issues regarding the informed consent process regarding these types of decisions. Patients may be inclined to make decisions based on medical professionals' recommendations, but the experiences that these medical professionals have would influence them to refuse the treatment themselves, having had more experience with the treatments on offer this may be some indication that these experiences are not being considered when the medical professional is giving a recommendation. There may be some information missing from their discussion with patients that the patient may need to make an informed decision.

The respondents in Olthuis and Dekkers' study indicated that meeting patient preferences contributes to the patient's well-being and also

[342] Kim and Lee, 2003, 627.
[343] Nurses tend to spend more time with individual patients than physicians do.

contributes to the patient achieving a good death. This is also clearly related to respecting patient autonomy. The participants in Olthuis and Dekkers' study did not explain precisely what they thought a good death for their patients would be, but they did acknowledge that patients' deaths can go more or less well for the patient. There may not be an explicit account of a 'good death' that the participants in this study were working with, but having observed various deaths they may have better insight than those working in other areas or outside of medicine.

Kim and Lee's study determined that while many professionals working in the field describe what is required for a 'good death' differently, they tend to focus on the quality of life the patient experiences while the patient is dying. Their study found "that nurses considered comfort, alertness, freedom from pain and being accepted and surrounded by family members were described as being features of a good death, whereas pain, loneliness, distress, nonacceptance and unpreparedness were described as features of a bad death."[344] This study found that nurses working in the palliative care setting describe a 'good death' as one that meets the criteria in the standard view, so acceptance of this view was made explicit in this particular study.

Patients express their preferences while planning and making decisions regarding their end of life care. It would seem that this feature (and by extension the involvement in planning and decision-making criterion (4)) has been added into well-being considerations and is not merely an aspect of respecting patient autonomy in Olthuis and Dekkers' study. Kim and Lee's research also indicates that many studies of healthcare professionals working

[344] Kim and Lee, 2003, 626.

in the palliative care or hospice setting consider involvement in planning and decision-making to contribute to a good death.[345] These studies share the view that helping patients to achieve a good death would require that the patient is involved in planning and decision-making regarding their end of life care and arrangements. Again highlighting the importance of respecting patient autonomy in what makes a person's death go well for them.

The importance of treating the patient as a person was highlighted in Olthuis and Dekkers' study. To treat the patient as a person is to acknowledge that the patient is a unique individual with a complex mix of beliefs, desires, wishes, doubts, emotions, goals, and hopes, and has had a life of their own with a past.[346] The individual that is being cared for is not a set of symptoms that needs to be treated. Treating the patient as a person may not appear to directly relate to the criteria proposed by the standard view, but treating the patient as a unique individual goes a long way to alleviating psychological and emotional suffering and distress, which is included in the second criterion of a good death (being as free as possible from physical, psychological, and emotional pain suffering and distress). The framework of Olthuis and Dekkers' study focused on the well-being and quality of life of patients, but treating the patient as a person also contributes to patient autonomy. Richards argued that autonomy is bound up in who we are, it is essential for self-esteem, integrity, and self-definition. All of the qualities highlighted as being important for recognising and treating the patient as a person are essential to who the patient is and develop along with their autonomy.

---

[345] Kim and Lee, 2003, 629.
[346] Olthuis and Dekkers, 2005, 317.

Jean Christopher Mino and France Lert argue that before entering into the terminal stage of their illness, patients are often considered a case of the biological manifestation of their disease that needs to be addressed, treated and cured. This biomedical view of the patient is not appropriate for palliative care because palliative care is a holistic treatment that treats more than the physical biological aspects of the patient.[347] Treating the patient as a person (as described above) is also important for respecting patient autonomy and giving weight to the patient's preferences. Treating the patient as a person is critical to addressing and alleviating more than just the physical aspects of pain, suffering and distress that are important for achieving a good death. Mino and Lert argue that treating the patient as a person is central to the holistic model of palliative care used in France.[348] The palliative care regime is designed by an interdisciplinary team of professionals who together look at the whole patient, as a person, to determine the best and most appropriate course of action for that person.[349]

The last two features that were identified by the participants in Olthuis and Dekkers' study as being important for patient well-being are completing life and dying well. The completion of life here refers to the patient having a sense of completion, though of course how this sense of completion is attained can vary between patients. It is within this feature that the presence of family and loved ones is mentioned (3). The respondents of the study indicated that having family and loved ones around allowed the patient to

[347] Mino and Lert, 2005, 228-229.
[348] Mino and Lert, 2005, 229.
[349] Mino and Lert, 2005, 228-232.

say good-bye and to seek the closure that the patient might need.[350] A patient cannot achieve a sense of completion without being aware that they are dying (1b), but this does not mean that the patient must be free of fear or anxiety. The patient can have a sense of completion but still feel fear, anxiety, regret, and have doubts about dying.[351] David P. Schenck and Lori A. Roscoe argue that spirituality and storytelling can help terminally ill patients to make sense of and find meaning in their life and impending death. Storytelling can help the patient to find closure and give them a sense of completion.[352] Finding meaning and having a sense of completion can go a long way to reducing the patient's psychological and emotional pain, suffering, or distress.

When the respondents in this study were discussing dying well they were referring to "the actual process of dying a patient undergoes"[353] This feature is important because death takes a while; dying is a process that can be quick, but often it takes longer. This reference to dying well is referring to that point in time at which death starts and ends at the point in which the patient is no longer alive (knowing precisely when that is may be impossible). Dying well refers directly to the management of pain, suffering, and distress of the patient (2), and it is the aspect that respondents referred to as contributing or being important to patient well-being that explicitly relates to the criteria of a 'good death'.

I have used Olthuis and Dekkers' study to show how the criteria for a 'good death' play a role in considerations for patients and the aims that palliative

[350] Olthuis and Dekkers, 2005, 318.
[351] Olthuis and Dekkers, 2005, 318.
[352] Schenck and Roscoe, 2009, 62.
[353] Olthuis and Dekkers, 2005, 315.

care professionals have to try to ensure that their patients have a good level of well-being or quality of life up until the time their life ends. This chapter also used Kim and Lee's study and Mino and Lert's study to support Olthuis and Dekkers' findings regarding views that healthcare professionals have about what constitutes a good death. These studies support my claim that the standard view of a 'good death' from the literature is supported in practice and influences the views of those individuals working in palliative care.

In the following two sections I will give some criticisms of the stand view. It is important to remember that the standard view is a view about what makes a death go well for the dying individual, and is not context dependent. There are two ways that the standard view can be interpreted. The first way that the standard view can be interpreted is to say that the criteria of a 'good death' are proposed as necessary and sufficient conditions to have a good death. The second way that the standard view can be interpreted is that the criteria for a 'good death' are suggestions or things to be considered when we are trying to help an individual's death go well for them. However, this second interpretation of the standard view does something different than the first. Instead of giving a conception of a 'good death' per se, it gives us things to consider, or suggestions in helping people to achieve a good death, without making claims about what a good death necessarily consists in.

These two interpretations have their strengths and weakness, but I think that the first interpretation of the standard view is problematic in ways that make it unacceptable. In the next section I will argue that, when the standard view

is interpreted in the first way, the standard view is false. I will then put forward a conception of a 'good death' that I think does a better job, fits better with our intuitions and ordinary notions about which deaths are good ones,[354] and makes achieving a good death more accessible to people. I will then address the second interpretation of the standard view. I will argue that this second interpretation of the standard view avoids many of the problems of the first interpretation and would fit well with the conception of a good death that I put forward.

II – The First Interpretation

The interpretation of the standard view as presenting a list of criteria for a 'good death' as necessary and sufficient conditions does get some support from responses found in the Olthuis and Dekkers study. This support is found both in the response about the different aspects that are important for promoting well-being in their patient and in the definition of well-being the respondents supported.[356] This shows that it is a valid interpretation of the view and should be considered.

[354] Beliefs about the nature and value of death vary between cultures and religions. I will give some examples about what these notions or intuitions might be. One thing that I think would be fairly consistent is that—*only* those who are terminally ill or whose health is such that we can say they are dying can achieve a good death—is false. There could be other intuitions about illness or health and the relationship they have to achieving a good death, but I think that most would agree with the falsity of this other statement.

[356] The respondents emphasised that well-being was a subjective evaluation made by their patients and that there was also objectivity in what contributes to well-being.

II.I –Achievement of Criteria Negatively Impact Well-Being and Autonomy

This first interpretation can run into problems quite quickly if we can show that achieving the criteria for a 'good death' has or can have a negative impact on an individual's well-being or autonomy. This is because a good death is supposed to be a death that goes well for the person who is dying, well-being is concerned with what makes a person's life go well for them, and a person is alive up until the individual's death has occurred. Achieving criteria that have a negative impact on the individual's well-being cannot help the individual's death go well for them. I will give several examples of how achieving some of the criteria for a good death can impact negatively on the individual's well-being, whether it frustrates other desires, prevents one from achieving some constituent of well-being or increases pain/suffering of some kind. This should demonstrate that for at least some people achieving the criteria for a good death would not result in a good death for them. This shows that, if the standard view is proposing these criteria as necessary and sufficient conditions, it fails to be applicable to a subgroup of people.

The respondents in Olthuis and Dekkers' study indicate cases when the presence of family and loved ones can be distressing for patients, but important for contributing to a good death.[357] For instance, consider a case in which the patient is seeking forgiveness or wishes to make amends for something and the family member the patient has confessed to do not forgive

[357] Olthuis and Dekker, 2005, 318 & 327.

the patient or becomes angry and leaves.[358] The patient is then distressed and does not attain the forgiveness they desired and their well-being may suffer for it. Even in instances when the exchange ends well and family members become closer it does not necessarily make the patient feel better.[359] If the patient regrets not having a good relationship with members of the family they can be encouraged, by staff, to try to work things out in hopes of fostering a sense of completion in their life. So the encouragement to have family present is not always confined to times when the patient's relationship with their family is a good one.

Other instances in which the presence of family can be distressful for patients that were discussed were when the patient has chosen a course of treatment or refused treatment and their family and loved ones disagree with the patient's choice and there is tension between the patient and their loved ones.[360] This tension can be very distressing and painful for both the patient and their loved ones. The family of the patient may even seek to override the patient's decisions in these instances, going so far as to seek legal assistance, infringing upon the patient's autonomy.[361] These types of cases can have a negative impact on the patient's well-being, but the presence of family is still required to achieve a 'good death'. The psychological and emotional pain,

---

[358] Olthuis and Dekkers, 2005, 318.
[359] Olthuis and Dekkers, 2005, 318.
[360] Olthuis and Dekkers, 2005, 318.
This example is not a statement about how the staff should respond. This example is about how family tension may arise from the patient's decisions and how this tension can impact on the patient's well-being. The Olthuis and Dekkers study indicated that staff did a lot to accommodate patient preferences, including non-medical preferences, like going outside, or seeing their horse again. The standard view would clearly include doing what patients want.
[361] If the family were successful in having the patient's decisions over turned, then unfortunately the staff would have to listen to what the family says instead of what the patient wants.

suffering, and distress experienced by the dying individual in these instances, while having a negative impact on their well-being, also means that the presence of family and loved ones (3) results in hindering the individual in achieving the second criterion, being as free as possible from pain, suffering, and distress. The second situation mentioned here also involves possible opposition to the patient's plans for their treatment and end of life care (4), which has an impact on both the patient's well-being and autonomy.

The respondents in Olthuis and Dekkers' study, while discussing the importance of the patient having a sense of completion, mentioned that this does not require that the individual does not feel fear, regret, or anxiety. It is true that an individual could have a sense of completion while still experiencing these feelings, but the knowledge that one is dying will likely add to the distress of the individual and it may be distressing enough to greatly reduce the individual's well-being. For instance, parents of a terminally ill child may withhold the fact that the child is dying from the child to spare the child from the fear, confusion, and sorrow that this information will bring to the child. The parents hope that withholding this information will prevent the negative impact that this knowledge would have on their child's well-being and the remaining time that they have left. These concerns would be the same for an adult, but it could be argued that the need for information is different. The adult must make decisions about their treatment (4), what types of treatments they are willing to have and for how long, and whether there are treatments or procedures that they refuse to have. The negative impact on the patient's well-being would still be there, but other considerations may be more important, such as having the patient's

consent. In these cases, satisfying (1b) can negatively impact on the patient's well-being, and it can also be seen as reducing their ability to achieve (2) as this knowledge is distressing and painful to the dying individuals in the examples.

The previous examples that I have used to show that achievement of these criteria can reduce or negatively impact on the patient's well-being and autonomy, have talked about how the achievement of the criteria could be distressing, painful, or could frustrate a desire of the dying individual. Now I will discuss the second criterion, which specifically looks at pain and distress. The aim of helping the patient to be as free as possible from physical, psychological, and emotional pain, suffering, and distress is admirable and looks as though it could not possibly negatively impact on patient well-being. However, achievement of this criterion in practice can be quite difficult. The methods used for pain and symptom management may reduce patient well-being through the drawbacks of using them. This is true using the analysis of well-being discussed in chapter two, but as the examples that will be discussed below will show, this is also true regarding how well-being was defined in the Olthuis and Dekkers study. The patient may be rendered unable to interact with their family and loved ones (3), or to exercise their autonomy if an unexpected medical need arises (4), and they may find the side effects to be quite distressing in themselves. The types of pain medication that we have available for our use can alter the individual's awareness (1a) and the patient can become confused and beyond comfort. In such circumstances the patient may not be experiencing physical pain, but they may be emotionally and psychologically distressed. These types of

reactions to pain and symptom management negatively impact on the patient's well-being and because of the states they induce these medications prevent an individual from exercising their autonomy. These situations can be very distressing for all parties involved. The goal of alleviating distress requires that we have better methods of pain management at our disposal and should be a cause for more research into how we can improve them.

In the examples I have given the achievement of the criteria for a 'good death' that are supported by the standard view have negatively impacted the patient's well-being and autonomy. The achievement of these criteria is supposed to ensure that the dying individual's death goes well for them, but if they reduce the individual's well-being it seems counterintuitive to claim that the achievement of these criteria does succeed in making the individual's death go well for them. In these examples, the achievement of the criteria for a 'good death', on this interpretation of the standard view, fails to bring about a good death for those individuals. Achieving the criteria for a good death should not make the individual's experience of their death go worse than it might otherwise have been.

What is required for a good death should be flexible enough that achieving it does not reduce the individual's well-being. The dying process takes time and the individual's well-being should be promoted through this time. If this means that they prefer to be alone or to have relatively little pain management so as not to suffer from some of its side effects, then the criteria of a good death should be capable of accommodating this. What might make one individual's death go well for them may not work well for another individual. In order to accommodate these differences between people, what

is required for a 'good death' needs to include respecting the individual's autonomy. Because people are different and what makes their death go well for them can differ I think that a 'good death' is one that promotes the dying individual's well-being as much as possible, and respects their autonomy for as long as possible. It is not a new idea to say that promoting or maximizing well-being at the end of life helps the individual's death go well for them, but I do think that the emphasis on autonomy makes this conception different. For some, at some stage during the dying process they may lose the ability to exercise their autonomy: they may be prevented from exercising their autonomy as a result of some treatment, or they may become unconscious, or there may be some other legitimate reason why they can no longer exercise their autonomy—and because of this we should respect their autonomy for *as long as possible*. These examples should give us good reasons to reject the first interpretation of standard view, but there are also other reasons to reject the first interpretation of the standard view.

II.II – Identification and Counterintuitive Implications

Identifying when death occurs or is occurring can be very difficult to pinpoint. Death is likely to be an event that is temporally extended, but identifying precisely when it starts can be difficult.[362] We can identify when death has occurred quite clearly, or at least there is a point at which we can say with confidence that someone is dead. Death might not occur at a particular instant, but the duration of time that it spans is not likely to be long. The question of when death occurs is not merely a philosophical problem; it can be quite difficult for those in the medical profession as well.

[362] Gilmore, 2013, 11-12.

Attempting to identify a certain number of systems or bodily functions that must be shutting down for death to begin seems a bit arbitrary for creating a definition and difficult to measure when applying it in practice.[363] So we are left with a fuzzy idea of when death begins, but a generally clearer image of when it ends. This being the case for death, determining when an individual enters into the dying process is often also very difficult. However, in some cases, such as with those who are terminally ill, it can be easier to identify when further treatment will be unable to restore health and the illness will lead to death.

If the standard view is meant to be a list of necessary and sufficient conditions for achieving a good death, then being unable to identify many people who have entered into the dying process would be problematic and lead to potentially counterintuitive implications. On the standard view, in order to achieve several criteria for a good death it must be clear that the individual has entered into the dying process. If the individual has not clearly entered into the dying process, then they cannot ensure that their family and loved ones are around (3); they are unlikely to know that they are dying (1b); and unless they have planned ahead they will not be involved in the planning of their end of life treatment and care (4). However, those who are not terminally ill may have no indication that they have entered into the dying process, which would mean that they are unlikely to achieve several of the criteria for a good death and on this interpretation of the standard view their deaths cannot go well for them. When thinking about individuals who may be unaware that they have entered into the dying process I am referring to

[363] Luper, 2016, online.

aging individuals whose health never really indicates that their life is coming to an end. It would be odd to endorse a view about a 'good death' that can only be achieved by a small subset of the population, like those who are terminally ill or who clearly entered into the dying process, and leave out many of those individuals who have lived a relatively healthy life—but this is precisely what the standard view does if the criteria it proposes are taken to be necessary and sufficient conditions for a 'good death'. The oddity here does not lie in there being a subset of the population who can achieve a 'good death', but who gets included and excluded from the subset.

If we are talking about a 'good death' it should be something that can be potentially achievable by most people, not only those individuals with an identifiable (often extended) dying process. A sudden death, at any time in life, would not allow an individual to achieve any of the criteria for a good death and in the palliative care literature a sudden death is often seen as a bad death.[364] Requiring that the individual go through an extended dying process in order to achieve a good death is counterintuitive. Why *must* a person experience a prolonged dying process to achieve a 'good death'? Why should those people who have an extended exposure to (what is most likely) a rather unpleasant experience before their death be the *only* ones who can achieve a 'good death'? It seems odd to say that the extended experience of something that is likely to be unpleasant is the best way to go about dying and the only way that the person's death can go well for them. But, if the individual is required to achieve each of the criteria of a 'good death' for their

[364] Kim and Lee, 2003, 624.

death to go well for them, this is exactly what the standard view would require.

Intuitions and ordinary notions about death can have a lot of variation between cultures and religions. Sometimes it is difficult to tease out notions or intuitions about what a good death is (a conception) and what would make a death go well for the individual whose death it is. If asked what a good death would be or what would make a death go well for someone some people would indicate that dying in old age in one's sleep is a good death or one that is quiet and free from pain.[365] These examples can be seen as both a statement about what a good death is and a statement about what would make a death go well.

> [P]eople usually refer to having a good death when they are about to die in old age and when they have completed their life's tasks and all their unfinished business… The duration of the dying process is another important criterion, reflecting the belief that death should occur at the proper time and be neither too abrupt nor unduly prolonged.[366]

This quote again can be seen as both giving an explanation of what a good death, but the last sentence also gives some guidance on what would make the death go well. Beliefs about what makes for a good death could be closely related to what makes for a good life, or beliefs about what happens after one dies. Some might believe that those who develop a terminal illness might

[365] While the sample size in this study is small it provides some evidence for the claim that people hold these views. Kim and Lee, 2003, 626.
[366] Mak and Clinton, 1999, 102.

need time to spiritually prepare for their death.[367] Things like how meaningful the individual's life and death are can come into play when thinking about what makes the death go well for the individual. What these notions and intuitions share is that it is not *only* those individuals who are terminally ill or easily identifiable as dying who can achieve a good death. A short death or one that occurs in one's sleep would not allow for the individual to achieve all of the criteria required of the standard view. If one dies peacefully in their sleep they are definitely unaware that they are dying (1b). However, a death that comes in old age in one's sleep is likely to have promoted well-being as much as possible and respected autonomy for as long as possible. This is also likely for those deaths that are quiet and free from pain, or have come at the end of a good life.

III – The Second Interpretation

According to a second interpretation, the standard view is not using the criteria for a 'good death' as necessary and sufficient conditions, but is instead presenting them as things that should be taken into consideration, or suggestions that may help one to achieve a 'good death'. On this interpretation, the preceding arguments against the standard view would not hold. If the criteria mentioned in the standard view are only to be regarded as suggestions or things to be taken into consideration for achieving a 'good death', then the criteria do not necessarily denote what makes a death go well for the person who is dying. This means that the arguments I presented earlier in favour of my conception of a 'good death' are not at odds with the

[367] This was a common belief in my grandmother's church group and one she took comfort in when my grandfather was diagnosed with terminal cancer.

standard view, but this doesn't mean that they are not valid arguments in support of a particular conception of a 'good death'. These considerations or suggestions can fit well into the conception of a 'good death' that I propose. A good death is one that promotes the dying individual's well-being as much as possible and respects their autonomy for as long as possible.

The difficulty of identifying when an individual has entered into the dying process may not be as problematic for the standard view on the second interpretation. If the achievement of these criteria is not required for a 'good death', then the counterintuitive implications I've just mentioned are also not an issue for the standard view. If achieving these criteria are taken as a suggestion and not a requirement, then the standard view does not imply the need for an extended dying process to achieve a good death. The second interpretation of the standard view could also coincide with the commonly expressed ideas about what constitutes a good death.

There can be a good reason for thinking that the criteria proposed by the standard view should be seen more as suggestions or things to take into consideration, because they are so often reflected in palliative and hospice care. It could be argued that the terminally ill or those individuals who can be clearly identified as having entered into the dying process have in some way gotten the short end of the stick in the sense that they are vividly aware of their impending death (1b). As this awareness and the prolonged dying experience are unpleasant, being surrounded by family and loved ones (3) and taking part in planning end of life care and treatment (4) can help the individual to cope or to relieve some of the distress that they are experiencing. If one remains relatively healthy and dies painlessly in their

sleep, then there would be no need for pain management. However, this is not likely the case for those individuals who are terminally ill or can be identified as having clearly entered into the dying process. So being free, as much as possible, from pain, suffering, and distress (2) is applicable in one set of cases, but not necessarily in the other. It would make sense to take pain, suffering, and distress of the terminally ill into consideration, while the relatively healthy individual does not seem to have this concern.

IV – Some Other Considerations

Olthuis and Dekkers' study mentioned *completion* as one of the aspects that promoted patient well-being and quality of life at the end of life.[368] The respondents in the study indicated that it was important for patients to have a sense of completion because this promoted well-being and helped the patients and their loved ones to cope. This idea of the importance of completion reoccurs when thinking about one's death. If one regards life as a project or narrative, then one might think there needs to be a completion stage or a final chapter. Once one has entered into the dying process it may be regarded as that completion stage in life. The suggestions made by the second interpretation of the standard view might help one to have this completion stage. The suggestions put forward by the second interpretation of the standard view might help the individual to shape this completion stage through their planning for their end of life treatment and care (4) and who they choose to be around them (3).

[368] Olthuis and Dekkers, 2005, 317-318.

David Schenck and Lori A. Roscoe argue that narrative can help individuals with a terminal illness to find meaning in their dying and it can be a useful means for helping them to cope with their impending death.[369] However, they do not argue that having a final chapter or completion stage is required for a good death. They simply argue that creating a life narrative and seeing the individual's terminal illness as an opportunity to create a final chapter can be a good method for coping with their illness or condition. Things such as being surrounded with family and loved ones (3) and planning for end of life care (4) might help one to find meaning in their death.

However, if a completion stage were required for one to have a 'good death', then it would run into similar issues with the identification problem I outlined above and would have the same counterintuitive implications of the standard view. Without the knowledge that one is dying it would be hard to know that you should be working towards completion. This would mean that many individuals who cannot be clearly identified as entering into the dying process would be unable to achieve a 'good death'.

V –Assisted Dying

Before we begin the discussion about assisted dying I want to first point out that the standard view does not rule out the possibility for assisted dying. An individual could meet all of the criteria/suggestions in the standard view and still choose assisted dying as an option. So arguments in favour of assisted dying could not be used to show that the standard view is false. However, the definition of palliative care does exclude the possibility for a patient to opt for

[369] Schenck and Roscoe, 2009, 61-72.

assisted dying as part of their care. Supporters of palliative care argue that with good palliative care there is no need for assisted dying. As the standard view gains a lot of support in the palliative and hospice care settings the presentation of the standard view was sketched with this in mind. However, it is important to discuss assisted dying when addressing end of life care.

There is much debate about the ethics of assisted dying and there are of course practical concerns about implementing policy if or when assisted dying is available. I think that the arguments in favour of the moral permissibility of assisted dying are strong arguments. This is one of the reasons that I emphasised the importance of respecting patient autonomy for as long as possible as being important for what makes a death go well for an individual.

One of the reasons that there is so much debate about the ethics of assisted dying is because it involves the killing of the individual who is being assisted to die. However, there is a bit of an asymmetry here. If our pets become very ill or their aging is perceived to have become overly burdensome to them, then pet owners may opt to have their pet euthanized, and this is viewed as humane.[370] The argument for this is that it alleviates the suffering of the animal at the end of their life. To justify this claim many point to beneficence; it is a benefit to the animal to not suffer. Many who believe that this is acceptable for our pets would not apply the same arguments to humans;

[370] 'Euthanasia' has fallen out of popular use, not because the idea has changed, but because of how general it can be. There can be voluntary, involuntary, and nonvoluntary euthanasia and it has now seems to have some negative connotations in public debate. 'Assisted dying' is more commonly used now. However, it seemed a bit odd to use 'assisted dying' when referring to pets because it seems to imply that the assistance was requested and that doesn't apply to animals.

what is viewed as humane for the treatment of our creature companions is not viewed as acceptable for people.

One might be wary of arguing from beneficence when arguing in favour of assisted dying. This is because depending on how the argument is presented beneficence may go too far. It can be greatly beneficial to the patient not to endure suffering and many deaths involve varying degrees of suffering, so one could argue that ending that suffering would be a benefit to the patient. However, this could be used to justify killing patients who are suffering and have not or cannot consented to ending their suffering in this way. Beneficence is meant to be balanced by nonmaleficence, but our duties not to harm might be fuzzy sometimes. Would it really be doing a harm to end someone's suffering through our actions? Without the patient's consent there is a definite difference between providing assistance in dying and killing the individual, but arguments based entirely on beneficence may allow for nonvoluntary or involuntary instances of killing. Is it really a harm to prevent or stop another harm from happening? It would depend on how you cash out harm and how much suffering is involved. The amount of suffering involved plays a role because in medicine we often balance the harm of a treatment or procedure against the intended or perceived benefit. Things like surgery involve harming the patient because they are invasive, but the expected benefit of the surgery can often justify causing the harms involved in cutting into the patient. If you cash out harm in a way that harm would include doing something to someone that they may not want or did not ask for, then these worries may be eliminated. In this case harm is entwined with autonomy, so in some sense nonmaleficence would require respecting patient

autonomy. Therefore the principle that is actually balancing beneficence in this case would be respect for autonomy and not maleficence. These concerns may also be eliminated if death is viewed as a harm or inherently bad for the person in question. If this is the case death can be viewed as a greater harm than the suffering that the patient is going through, so concerns for beneficence would always be outweighed by maleficence because death is a harm.

One argument that is often presented against assisted dying is that there is a moral distinction between killing and letting someone die, or doing and allowing. The first is viewed as an action with the intent to end someone's life, it is active, while the other is viewed as passive, it is allowing them to die. Allowing someone to die involves knowing that the individual will die without intervention or if you cease treatment, but the physician takes no active steps to help the process along.[371] In the medical context withholding or withdrawing treatment is viewed as allowing someone to die. Withholding or withdrawing treatment is based on the patient's refusal or request for the treatment to be stopped; thereby, supported by respecting patient autonomy. The refusal or withdrawal of life sustaining treatment will inevitably hasten the patient's death, but this is permissible. The permissibility of this hastening of the patient's death is grounded in respecting the patient's autonomy. L. W. Sumner's argues that you can make an extensionist argument from the permissibility of hastening death through withdrawing or withholding of treatment to the permissibility of assisted dying if you can show how each of the steps along the continuum between the two are permissible "*when all other*

[371] Sumner, 2011, 92.

relevant factors are equal."[372] He begins by arguing for the permissibility of withholding or withdrawing treatment. The act of withdrawing or withholding treatment is typically at the request of the patient (when they are able), so involves informed consent and respecting the patient's autonomy.

However, Sumner argues that this distinction between doing and allowing, or active and passive, does not do all it needs to do to explain the ethical difference between the two. This distinction may work for cases when the physician ceases a patient's chemotherapy when it can no longer benefit the patient, which looks like it is allowing the patient to die of cancer eventually. Some methods of withdrawing treatment are not passive, they require action. So, the ethical distinction must draw the line between doing and allowing, or more precisely doing something and doing nothing. But again methods of withdrawing treatment require doing something, so the distinction cannot be viewed as an act/omission distinction.[373] But, we need to be able to make some distinction that shows that there is a difference between the physician giving a patient a lethal dose of medication resulting in the patient's death and the physician who disengages a ventilator resulting in the patient's death. In the argument presented below Sumner's shows that the difference cannot be the intention involved, or causation because both courses have the same result. Perhaps the distinction lies in some normative judgement, which would rely on some "normative concept that determines cause of death on the basis of a prior determination of whether the physician's action was justifiable."[374] However, this cannot work either because the ethical

[372] Sumner, 2011, 87 & 91. Quoted portion from 91.
[373] Sumner, 2011, 93.
[374] Sumner, 2011, 94.

judgement about distinction between killing/allowing to die is relying on a presupposition about the ethical difference between the two categories. This being the case, Sumner concludes that, "[i]t is by no means obvious, therefore, that there is any coherent non-normative basis for the 'active/passive' (killing/letting die) distinction."[375] So, arguments against assisted dying that rely on this distinction do not hold.

Administering treatments that are known to shorten life, but are intended to alleviate suffering can also fall into this latter category. However, it is important to note that the intention in administering the treatment is not to hasten death, but to alleviate suffering. This is often covered under the doctrine of double effect. The doctrine of double effect says that there are two effects to administering some treatment X, there is a good effect and a bad effect, both are foreseeable, when administering X the intention is to have the good effect and we have a serious reason for implementing a treatment that has both this good and bad effect.[376] Sumner argues that the doctrine of double effect has three conditions that must be met: intention, causation, and proportionality. Intention requires that the aim of the physician in providing X is the good effect. Causality requires that the good effect is not the causes by the bad effect. Proportionality requires that there is a proportionately serious reason to bring about the bad effect.[377] Sumner wants to focus on a case relevant to palliative care so he uses an example of a terminally ill patient who does not want to experience any undue suffering and has chosen to undergo continuous deep sedation. The good effect here is that it reduces

[375] Sumner, 2011, 94.
[376] Sumner, 2011, 57.
[377] Sumner, 2011, 57

her suffering and the physician suggested it with the intention of reducing her suffering (motivated by compassion). The bad effect is that continuous deep sedation hastens death.

Sumner argues that the doctrine of double effect "presupposes a deontological ethic with a strong 'sanctity-of-life' principle which generally prohibits killing (or at least killing humans)."[378] The doctrine of double effect serves to provide a justification for these instances to be an exception to the general principle against killing. However, he argues that a consequentialist account may come to different method of determining when there is an exception to the general prohibition against killing, like some sort of case-by-case judgement. This judgement may be influenced by what explanation for the badness of death is being utilized or is correct. Sumner strongly endorses the depravation account, which states that death is bad because it deprives the individual of the (intrinsic) goods of life.[379] So, essentially the badness of a person's death depends on what kind of life they are being deprived of; if the quality of that life will be sufficiently low, then their death would be less bad or may not be viewed as a harm at all. This can change our value judgements about the good and bad effects of treatment X.

Sumner is highly critical of the intention condition in the doctrine of double effect. He first uses some empirical research to demonstrate that practitioners do not approach the intended/foreseen distinction as a dichotomy, but more as a continuum. Their responses to researchers typically highlighted multi-

[378] Sumner, 2011, 58.
[379] Sumner, 2011, 58.

layered intentions, or are "unwilling or unable to clarify whether the patient's death was an intended or a merely foreseen outcome."[380]

Furthermore, Sumner argues that even if the doctrine of double effect were capable of drawing a distinct line between intended outcomes and foreseen outcomes, then there can be a challenge from a different direction. If a foreseen outcome, such as hastening death, is certain and predictable, then one can wonder if it is possible to say that the outcome is not intended.[381] Sumner gives a non-medical example to test this intuition. Say that as assassin wants to kill the Grand Duke and decide to do so by throwing a bomb into his carriage. The assassin knows that the Grand Duchess will also be in the carriage, so by throwing the bomb in the carriage you know that you will also be killing the Grand Duchess. The assassin is successful in throwing the bomb into the carriage and killing both the Grand Duke and Duchess. The assassin clearly intended to kill the Grand Duke, but the question is did he also intend on killing the Grand Duchess?

Sumner argues that there can be two ways to answer this question.[382] The first is that the assassin continued with his plan knowing that the Grand Duchess would be there instead of seeking a different opportunity to kill the Grand Duke, so we cannot say that her death was unintentional, and if not unintentional, then it must be intentional. The second approach maintains that the Grand Duchess's death was a side effect or by-product of the Grand Duke's death. Had the Grand Duchess not been in the carriage, then the assassin's plan would have gone along exactly as it had and only the Grand

[380] Sumner, 2011, 64.
[381] Sumner, 2011, 65.
[382] Sumner, 2011, 65.

Duke would have died. So, this example illustrates that as far as the assassin's plan was concerned there is some significant difference between the two deaths, one was intended and the other was foreseen. To get to the bottom of this question Sumner argues we need to tease out some ambiguities of our notion of intention. In one (broader) sense an individual will be seen to intend all the consequences of their actions that they can foresee as certain or possible, but this sense would not be suited when discussing the doctrine of double effect because it would imply that both the good and bad effects are intended. "But we also have a narrower sent in which intending some outcome is related to wanting, or desiring, or welcoming it."[383] However, this narrower sense does not work with the assassin example because it implies that the assassin the outcome was desired by the assassin, but he may have felt that the act of killing the Grand Duke (or anyone) was vile, but a necessary part of his larger plan; the death was a means to an end. This narrower sense of intention places it within the context of a plan, but plans typically include steps and each step is intended to reach the end or goal. This narrower sense of intention maintains the intending/foreseeing distinction because the foreseeable effect does not factor into the successful completion of the plan.

Sumner turns back to his continuous deep sedation example now and proposes a second plan. Imagine the patient has requested the continuous deep sedation so that she will not need to experience any undue suffering and because it hastens her death, so both effects of the treatment are intended by the patient. The physician is still motivated by compassion and intends to

[383] Sumner, 2011, 66.

alleviate the patient's suffering, but this example now also includes an intention for the 'bad effect'. Sumner argues that we tend to think that the two cases are morally different, but wonders where the moral significance should be placed. Sumner argues that both plans are the same in two ethically salient features, the motive in both cases is compassion and the outcome in both cases is the same. The difference between the plans is that in the second plan the patient's death is intended. If deep continuous sedation is better for the patient on both plans, then the change in intention does not appear to be an ethically salient feature.

Sumner argues that the ethical permissibility of assisted dying is based on "two basic values: patient well-being and patient autonomy."[384] He argues that the well-being argument is based on the proposition "that suffering is intrinsically bad and is therefore something to be prevented or relieved."[385] Assisted dying will help patients to eliminate their suffering without anyone else incurring comparable costs. Because of this he argues that there is a strong ethical case in favour of assisted dying being an available option. Palliative care aims at providing adequate pain management, but there is more to suffering than physical pain, and not all physical pain can be managed effectively. This is not just referring to emotional and psychological aspects of suffering, but also other physical sensations that can contribute to suffering like: "nausea, dizziness, itching, fatigue, shortness of breath, and so on."[386] Palliative care aims to relieve suffering in patients and that this suffering calls for a response and intervention. Sumner argues that the

[384] Sumner, 2011, 87.
[385] Sumner, 2011, 87.
[386] Sumner, 2011, 88.

argument for the justifiability of assisted dying from well-being can be given from both a consequentialist and deontological perspective. There is one ethically salient fact that remains when thinking about terminally ill patients and that is that they are suffering and that their continued suffering can be prevented and that by choosing to seek out assisted death the patients in question want to prevent further suffering by hastening their death.[387] Provided that the patients in question are fully informed and fully competent to make their own decisions; this option should be available to them and any request for it should be viewed as them exercising their autonomy. Sumner argues that the autonomy grounds the second argument in support of assisted dying. As we have seen earlier in this chapter planning one's end of life care is viewed as being important for palliative care and I have argued that respecting patient autonomy is important for an individual's death going well for them. Sumner argues that autonomy is required for being an active manager of one's life and this involves living in "accordance with one's deeply held goals and values."[388] Sumner argues that autonomy and well-being are both served by the informed consent process and this includes not just consents, but refusals as well. Managing one's dying process includes determining which treatments to consent to and which one wants to refuse and this applies to requests for treatments as well. Sumner argues that if a patient requests end of life treatments that hasten death, like the request for continuous deep sedation discussed above, these requests should be respected. If this is the case for life shortening treatments meant to reduce suffering, then this should hold for assisted dying as well. Sumner argues

[387] Sumner, 2011, 89.
[388] Sumner, 2011, 89.

that these general arguments can be supported using consequentialist arguments as well as deontological arguments. The consequentialist could argue that the best interests of the patient can be accommodated through accepting the request for assisted death to alleviate further suffering, and where accepting this request is both in her best interests and autonomy we have more reason to accommodate the request. The deontologist can argue from different duties like the duty not to inflict avoidable suffering, or duties of care, and rest their argument on the patient's right to self-determination.[389]

Arguments from well-being and autonomy can provide the basic justification for assisted dying, but these arguments cannot show that it is always justified. These arguments can only justify assisted dying under appropriate conditions.[390] Sumner argues that assisted dying is only justified when five conditions are met: request, capacity, voluntariness, disclosure, diagnosis.

> *Request*. Because both treatment options are voluntary, they must be requested by the patient and not on the patient's behalf by a substitute decision-maker.
>
> *Capacity*. The patient must be decisionally capable at the time with respect to the treatment option in question. Decisional capacity included the ability to understand and appreciate the nature and consequences of requesting a therapeutic intervention that is intended to cause death. While decisional capacity must be the default presumption for adult patients, it is rebuttable by evidence of either some standing mental illness or disability or some situational factors

[389] Sumner, 2011, 89-90.
[390] Sumner, 2011, 90.

serious enough to impair cognitive functioning. The relevant decisional capacity for assisted death is the ability to make reasoned decisions *with respect to this kind of treatment.* A person may be competent to make other personal decisions (such as financial ones), or even other treatment decisions, but not this one.

Voluntariness. The patient must be free of undue influence and coercion, whether by providers or by family members. I is recognized, of course, that our decision-making as patients will often be influenced by what others think or suggest or by our knowledge of what they want or would prefer. Since it would aim much too high to purge decision-making of all such influences, the issue of voluntariness will turn on when such influences are 'undue'—that is, when they rise to the level of fraud, deceit, duress, or any other form of coercion. As with decisional capacity, there will inevitably be borderline cases in which the voluntariness of a patient request for assisted death is uncertain.

Disclosure. The patient must be provided with adequate information concerning the treatment options in question. This information will normally include the patient's diagnosis and prognosis in the absence of treatment (including any uncertainty attending these matters), the nature of each available treatment options, the probable outcome for each option, and the risk attached to each option. The general rule for disclosure is that it should include all the information a reasonable person *in this particular patient's circumstances* would need in order to make a reasoned decision concerning then treatment in question.

> *Diagnosis*. The patient must be diagnosed with a medical condition (an illness or disability) serious enough to warrant consideration of treatment options that will hasten death. The condition may, but need not, itself be terminal. The patient must be experiencing a degree of suffering that he regards as intolerable and which cannot be alleviated to the patient's satisfaction by any treatment option that will not also have the effect of hastening death.[391]

Capacity, voluntariness, and disclosure fall in line with the standard conditions for informed consent discussed in the previous chapter. Sumner argues that request also falls in line with standard conditions for informed consent, but the fifth condition is unique to treatments that will hasten death, and assisted dying. The need for the final condition is because of the type of treatment assisted dying is; death is permanent, irreversible, and final.[392] This being the case, he formulated the fifth condition so that it would require that other treatment options have been exhausted or been refused by the patient because once treatment is administered the patient no long has an opportunity to change their mind or rethink their choice.[393] Sumner says that there is a mild degree of paternalism worked into these conditions, which ensures that the individual is not requesting assisted death prematurely, so there is "some privileging of patient well-being over autonomy."[394]

I agree with the arguments that Sumner puts forward and I think that assisted dying should be available to those individuals who would like to

---

[391] Sumner, 2011, 90-91. Author's original emphasis.
[392] Sumner argues that the fifth condition should also be applied to any treatment request that will hasten death.
[393] Sumner, 2011, 91.
[394] Sumner, 2011, 91.

choose it. I think that the conception I argued for about what makes a death go well for the individual whose death it is fits with the arguments presented for assisted dying. Above I argued that where possible more weight should be given to autonomy in the formulation of a 'good death' that I put forward. I bring this up because Sumner claims that his conditions are a bit paternalistic and this was done on purpose to privilege patient well-being over their autonomy, so one might think that the conception of a 'good death', which allows for more weight being put on autonomy, may conflict with conditions that favour well-being. I don't think that it does. I think that if an individual is going to request assisted death, then their autonomy should be respected, but I also think that the conditions that Sumner outlines are the appropriate conditions to require such a request to meet. I agree with Sumner that because of the type of treatment assisted dying is that people may need the extra bit of protection and concern that the conditions have built into the decision-making process.

The conception of a 'good death' put forward was developed in the earlier part of this chapter, while, working within the palliative care framework, as defined by the World Health Organisation. I wanted to make sure that the conception of a 'good death' that I put forward would also work with assisted dying. I think that there are good well-being based arguments that can be made in favour of assisted dying, but I think that these arguments also need to be balanced by arguments from autonomy. Sumner uses arguments based on both principles throughout his book. However, a concern for patient well-being is frequently cited as one of the reasons that assisted dying is not an option available to people. This is one of the reasons I wanted to put a bit

more emphasis on autonomy in the conception of a 'good death' I have presented. This is in part because I think that it is important for people to have a say in how they die, and because it was largely developed with terminally ill or those whose health is in a steady and persistent decline in mind, but also because I think that it can apply to those individuals who remain relatively healthy until they die. I think that it does a better job at applying to people in both categories than other conceptions about what makes a death go well for the individual who is dying.

VI – Conclusion

A good death is one that goes well for the person whose death it is. I argue that a good death is one that promotes the dying individual's well-being as much possible and respects their autonomy for as long as possible. I think that the first portion of this requirement follows from what a good death is supposed to be. Dying is an experience that an individual has while they are alive, and death has occurred once the individual ceases to be alive. Well-being is what makes a person's life go well for them and this extends until they cease to be alive. So promoting well-being as much as possible until the individual ceases to be alive would help the person's death go well for them. I have included respecting autonomy for as long as possible because the individual's autonomy and their consent is morally significant, which I have argued for in detail in chapter three. I concede that at some point during the dying process the individual will likely lose the ability to exercise the capacities required for autonomy. Respecting those choices that were made prior to this point is important, but once they can no long exercise their autonomy respecting their autonomy becomes really quite limited. One can

make forward looking decisions and give consent for future treatments and these decisions should be respected. Helping an individual to achieve a death that goes well for them will involve promoting their well-being and respecting their autonomy, but how long we can do both for will vary between people.

I have argued that the standard view of a 'good death' that appears consistently in the literature can be shown to be shared with those working in palliative care, even if they do not explicitly endorse the view as such. I have shown this through the use of studies conducted in palliative care. I have argued that there are two interpretations of the standard view. The first interpretation of the standard view, which regards the criteria as required for a death to be a good one, is problematic. The achievement of some of the criteria can have a negative impact on the dying individual's well-being, and since well-being is how well an individual's life is going for them, a negative impact on this would hardly result in their death going well for them. The first interpretation of the standard view is also counterintuitive in its implications about the scope of people who could achieve the criteria required for a 'good death': it implies that this is achievable only by those who are terminally ill or who can be clearly identified as having entered into the dying process. This means that those individuals who remain relatively healthy throughout their life and cannot be clearly identified as having entered into the dying process would be unable to achieve a 'good death'.

I argued that if the standard view were interpreted not as a list of criteria required for to achieve a good death, but instead as a list of suggestions or things to take into consideration to achieve a 'good death,' then the view

would not be problematic. However, if the standard view were interpreted in this way, then it would not be presenting a conception of a 'good death' at all. On this interpretation, the standard view would be making suggestions to help a person's death go well for them and not stating what is required for the death to be a 'good death'. This being the case, the second interpretation of the standard view could be complementary to the conception of a 'good death' that I put forward. Interpreting the standard view as a list of suggestions would fit well with a 'good death' as being one that promotes the dying individual's well-being as much as possible, while respecting their autonomy for as long as possible.

The end of this chapter discussed Sumner's arguments about the moral permissibility of assisted dying. I am in agreement with Sumner's arguments and think that assisted dying should be offered in end of life care. Sumner proposes five conditions that must be met for a patient's request for assisted death to be accepted. Three of these conditions relate to the standards of informed consent presented in chapter three, I did not discuss requested treatments in that chapter, but the request condition also relates to our standards of informed consent. The fifth condition Sumner argues applies to assisted death specifically, but should also be considered when the treatment option hastens death. Sumner uses arguments from well-being and autonomy to argue for the permissibility of assisted dying. The arguments presented fit well with the conception of a 'good death' put forward in this chapter.

Genetic Testing

Our genes are uniquely our own: unless one has an identical twin, no one in the world has the exact same genetic make-up as we do. But our genes also connect us to our relatives and ancestors. We are created from half of each of our parents' genes and we will pass on half of our genes to any child that we create. This means that as much as our genetic make-up is uniquely ours in some sense it is also shared among our family. When it comes to genetic testing the results will in one sense be the tested individual's, but in some sense the results are not just theirs, but their family's as well. If an individual has a genetic condition or disease, or a susceptibility to developing a disease or condition, the genes responsible were likely inherited. For example, genetic testing for an inherited susceptibility to cancer[395] can tell us whether we are at an increased risk of developing cancer in the future, but it can also indicate that some of our relatives are also at an increased risk of developing cancer.

There are clear health benefits to the early detection of cancer. Early detection can result in shorter, more effective treatment regimens and an increased life expectancy. For this reason, early detection is usually beneficial to the health of the patient.[396] Genetic testing can help to identify those individuals who

[395] For the purposes of this chapter I will refer to genetic testing for an inherited susceptibility to cancer as genetic testing. I will also refer to an inherited susceptibility to cancer as an inherited susceptibility.
[396] Early detection is beneficial to most patients, but there is a subset of patients who have cancers that will never be symptomatic (these cancers would have never caused them issues). For this subset of patients, treatment for cancer may be more harmful

are at an increased risk of developing cancer. Once identified a regime of frequent screening is recommended (in most cases) to increase the likelihood of early detection. Genetic testing can have some clear health benefits for those individuals who have an inherited susceptibility, but there are also broader positive and negative impacts on well-being and autonomy. These broader implications need to be taken into consideration when determining whether this type of testing should be offered. Genetic testing of this kind is unique in this thesis because the tested individual need not be in a state of unhealth to attain testing, and their test results do not indicate that they are in a state of unhealth, at least so long as they were healthy when they took the test. The individual who undergoes this type of testing is by all accounts healthy and in theory remains healthy even after a positive test result, and this would be true on many theories of health. This differs from the previous chapter since the terminally ill individual is in a state when their health is in a steady and persistent decline.

This chapter will focus on the impact that genetic testing can have on the tested individual's well-being and autonomy. I will approach this investigation first by giving some background on what genetic testing entails. The first section will discuss what physicians look for before recommending genetic testing, and the procedure involved, and it will also flag up some

---

than good in that we are treating a condition that would not have had an impact on their health. Unfortunately, our current screening technologies/methods cannot make a distinction between cancers that will be harmful if not treated and those that would be asymptomatic. Early detection in individuals who have a terminal prognosis can give the individual the opportunity to prepare for their death. This may include planning their end of life care, which they may not have thought of at this point in their life, and putting their affairs in order. These things can be seen as a benefit to early detection, but the knowledge that one will die sooner than they may have thought can also cause a lot of pain and distress for the individual.

ethical issues that arise from testing that will be discussed later in the chapter. Once the patient has been given a positive test result, determining an accurate risk assessment for the individual requires an in depth personal medical history and the medical history of any family members that have had cancer. The second section will look at how we might understand an individual's risk. It is generally agreed that an individual with an inherited susceptibility has a greater risk of developing cancer at some point in their life than individuals without an inherited susceptibility. However, it is not quite clear how their increased risk might play out.

I will then move on to discuss reasons why people might seek out genetic testing of this kind in the third section. Reasons for seeking this kind of testing can vary. How the individual obtains this type of testing may depend on the reasons for seeking testing and whether an individual has a physician recommendation. A physician recommendation can determine whether the testing may be offered through their healthcare system or must be sought out privately, or whether the individual decides to purchase a genetic testing kit. These different avenues of receiving testing may pose different issues, such as worries concerning informed consent.

This thesis does not subscribe to a particular theory of well-being and as such the discussion of the possible impacts to well-being will be quite general. However, both the costs and benefits that an individual may experiences can be translated into a specific theory of well-being if need be. Possible benefits or costs may impact on the pleasures/pains that one can experience; they may form more informed desires or their desires may be frustrated with the knowledge that this kind of testing can provide; or these costs and benefits

may have implications for the individual's ability to attain or to what degree they can attain things on an objective list. Section four will look at why genetic testing might be beneficial for the tested individual and how it may benefit them. This section will look at the positive impact that testing of this kind might have on the tested individual's well-being and ability to make informed decisions. Once the possible positive implications of this type of testing have been considered I will move to consider the potential negative impact that this type of testing can have on the individual's well-being and autonomy, in section five.

Some of the possible impacts discussed in these sections mirror some aspects of illness that are discussed in phenomenological accounts of illness, such as, social dimensions of illness, relationships with others, alterations in one's perceived options, and some similarities in one's relationship with their own body and their self-identity. I've drawn on this research because I think that there are some parallels in the lived experience that both groups have. In chapter one I argued that I do think that a theory of health should be phenomenologically informed and tentatively suggested that a complete combination theory of health would incorporate a phenomenological account of illness. I as of yet unsure if the parallels that I have drawn on between illness and the types of lived experiences that tested individuals may have would speak to these individuals as potentially being ill as a result of testing. As the remarks about a phenomenological account of illness being incorporated into the combination theory were very preliminary I think that issues highlighted in this chapter might be very important to developing the theory further.

In section six I will discuss some of the ethical implications that this type of testing can have relating to informed consent and autonomy. I will argue that genetic testing can be a transformative experience of the type that L. A. Paul discusses in her book *Transformative Experience*.[397] As such, it can be difficult to make an autonomous decision to undergo genetic testing. I will argue that the best way that we can respect autonomy where genetic testing is concerned is through offering genetic counselling to the individual, both before and after testing.

Section seven will argue that the possible impact on the screened individual's well-being and autonomy should be considered when we are determining whether to make this kind of testing available. Often the criteria used to determine whether a medical or health product or service should be offered focus on how effective or accurate the service or product is and the health benefits or harms that are involved in its use. This chapter will conclude that, taking into consideration the possible negative impacts to individuals' well-being and autonomy, we should limit the means by which people can access genetic testing to those that include genetic counselling as part of the testing procedure.

For the purpose of this chapter I will assume that the only people with access to the individual's genetic test results will be the individual and their physician. The question of whether this information should be shared with third parties is complex. Currently this information is regarded as being private. Confidentiality of these kinds of test results can bring up complex ethical questions. Matters of who should be granted permission to have

[397] Paul, 2014.

access to an individual's genetic test results can have a large impact many areas of these individuals' lives. The areas that can be impacted on the individual's life can vary and the potential limitations that can result can have further implications for the individual's well-being and autonomy than those discussed in this chapter. Genetic test results of this kind, if third parties were to have access, can impact on an individual's ability to get both medical and life insurance. This limitation not only affects one's ability to potentially provide for loved ones if they were to die, but it can also put limitations on one's ability to procure financial services such as large loan or mortgages to purchase a home. If future employers were privy to an individual's test result the individual may find themselves with limited opportunities for employment or the types of careers that they may wish to pursue.[398] Since the scope of issues that relate to confidentiality is so large and, I think that the issues are further complicated by the multifactorial nature of cancer, I think that the focus on the individual's well-being and autonomy will get side tracked. I think that there are some really interesting impacts on the individual's well-being and autonomy that testing itself can have that these issues deserve their own investigate. However, even under the assumption that the test results are available only to the tested individual and their physician we can still find some interesting concerns about confidentiality. These arguments will be presented as though the only parties privy to the test results are the physician and the tested individual, because the scope of this

[398] There is some evidence that this is a possible concern, at least if discrimination disclaimers on job adverts are any indication. While looking at job adverts for academic positions in the United States I've noted that they include genetics along with things like age, sex, and race in their equal opportunity statements.

chapter does not allow me to address issues concerning third party information sharing here.[399]

I - Genetic Testing for an Inherited Susceptibility to Cancer

Current medical science has identified genes or gene variants that indicate an increased risk to developing some cancers—such as breast, ovarian, prostate, bowel, and colorectal cancers, soft tissue sarcomas, leukaemia, and childhood cancers.

Genetic testing is a rather expensive procedure.[403] The expense of this process is not only determined by the procedure itself, but also includes the genetic counselling and time required to help patients to understand the test and results. Due to the time and expense required for this type of procedure, determining who would benefit most from receiving genetic testing is important. The individuals who would benefit most from this type of testing are those individuals who have an inherited risk, meaning those individuals who carry the genes or gene variants that will increase their risk of developing cancer. To determine who these individuals might be, physicians have identified indicators that may or are likely to point to an inherited susceptibility to cancer.

---

[399] Ronald Dworkin's discussion of the insurance problem (2000, 433-437) as well as concerns regarding discrimination in employment would apply here. I would speculate that these types of concerns may also be reflected in a reduction of well-being for the tested individual and possibly any dependants that they have.

[403] Hodgson and Evans, 1998, 15-17.
While prices have decreased since 1998 it is still quite expensive. However, this may depend on what your disposable income is. In her 2015 book Nessa Carey says that you can have your genome sequenced for $6000, this is just for sequencing (2015, 27). More recent costs in the UK are estimated to cost £100-£1000, not including a consultation fee of £200-£350. It is important to note that this price range is provided by a source discussing both direct-to-consumer testing and private genetic testing. Accessed December 20th 2018.
https://www.geneticdisordersuk.org/aboutgeneticdisorders/genetictesting

I.I – Physician Recommendation

Physicians look for indicators in an individual's family medical history that can be associated with an underlying genetic susceptibility to a particular type of cancer. Relevant indicators include things such as a family medical history in which a number of close relatives have developed a specific type of cancer over a number of decades;[404] those individuals who have developed a specific type of cancer at a younger age than it might develop in the general population;[405] the number of relatives who have developed multiple cancers;[406] and the number of tumours found in those relatives' first cancer.[407] When considering a younger age of onset, we are looking at cancers that typically develop later in life, such as breast and prostate cancer.

However, some of these indicators can be present in cases that would not indicate an inherited susceptibility to cancer, but could be the result of some environmental factors. A physician may also recommend that an individual seek genetic testing if a relative has a positive test result from their own genetic test. Under some healthcare systems genetic testing with a physician's recommendation is covered by the healthcare system.[409]

I.II – Procedures

A referral from a physician is followed by genetic counselling. Genetic counselling occurs both before and after genetic testing. The genetic counsellor will seek to ensure that the patient's autonomy and personal

[404] Hodgson and Evans, 1998, 3.
[405] Hodgson and Evans, 1998, 4.
[406] Hodgson and Evans, 1998, 13.
[407] Hodgson and Evans, 1998, 4.
[409] One such system is the NHS in the UK.

choices are promoted, their privacy is maintained, their test results are confidential, and that the patient will have access to resources that they are entitled to.[410] In the pre-testing counselling session the individual is given information on the testing procedure as well as information regarding the risks, benefits and limitations of genetic testing.[411] It is during this time that the genetic counsellor will also discuss with the individual how the result of the genetic test might affect the individual's life and relationship with their family. At this time the individual is also asked to consider whether they would want the results of their test to be disclosed to relatives who might also be at risk.[412] There is a discussion on how the test results can be used to make an assessment of the tested individual's risk of developing cancer. The individual can then determine whether they would like to undergo genetic testing.

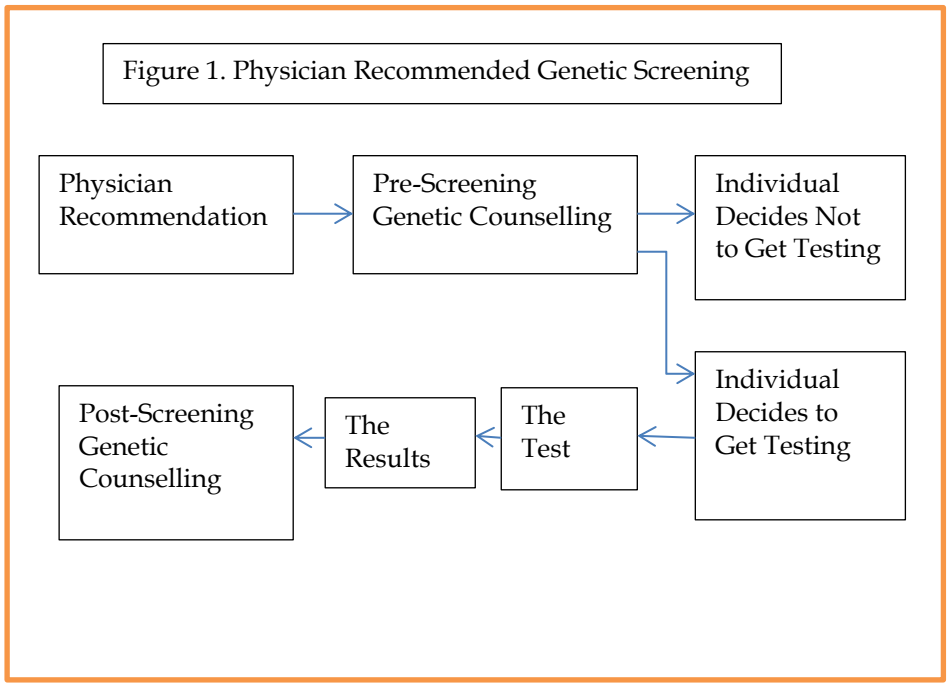
Once the test results come back the individual returns for genetic counselling where they go over the results and what they mean for the individual. They may discuss the likelihood of passing these genes on to their children and the reproductive options that are available to them.[413] The individual is also given advice to reduce their risk of developing cancer, such as living a healthy lifestyle through exercise and diet, and avoiding things that are

---

[410] Suthers, 2008, 34.
[411] "Genetic Testing and Counselling" Accessed March 1st 2017 http://www.nhs.uk/Conditions/Genetics/Pages/genetic-testing-and-counselling.aspx
[412] "Genetic Testing and Counselling" Accessed March 1st 2017 http://www.nhs.uk/Conditions/Genetics/Pages/genetic-testing-and-counselling.aspx
[413] "Genetic Testing and Counselling" Accessed March 1st 2017 http://www.nhs.uk/Conditions/Genetics/Pages/genetic-testing-and-counselling.aspx

associated with causing cancer like smoking and drinking alcohol, and they may then be encouraged to participate in a frequent screening regime.[414]

Figure 1 illustrates the steps that the patient will go through to get genetic testing with a physician recommendation. The diagram loops back to the physician's recommendation because discussion of some of the patient's lifestyle changes can be discussed in counselling, like diet and exercise, while others, such as frequent screening, will be organised by the physician.



Following a positive test result, the medical professional will aim to make a personal risk assessment for the patient. To make an accurate risk assessment for the tested individual, further detailed information about their family's

[414] NHS Predictive Genetic Tests For Cancer, Accessed March 1st 2017 http://www.nhs.uk/Conditions/predictive-genetic-tests-cancer/Pages/Introduction.aspx.

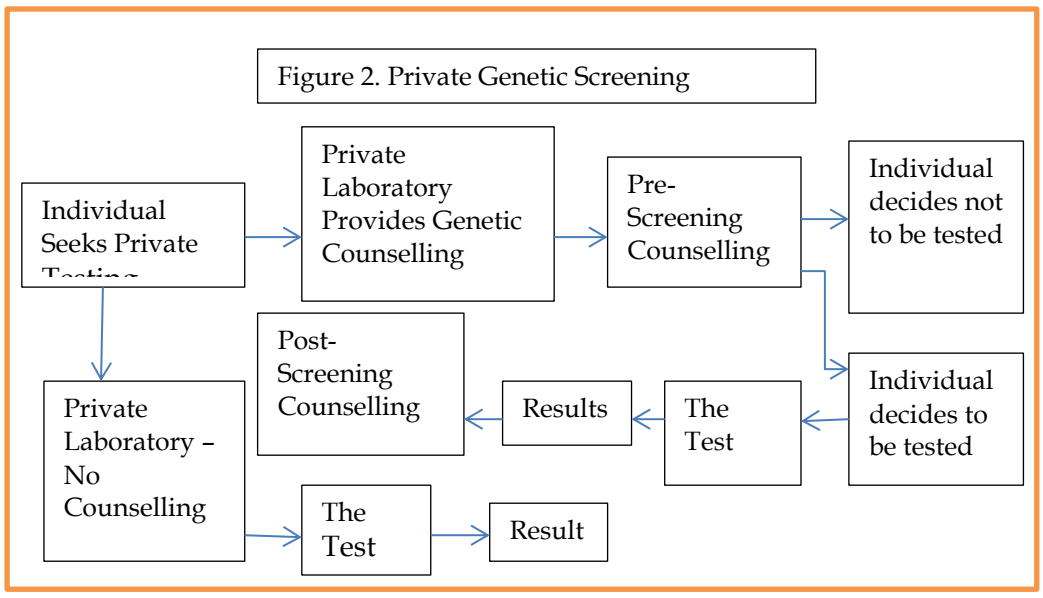
medical history, particularly medical histories concerning cancers, is needed along with information provided by their test result.

To access the in depth medical information needed to make an accurate risk assessment for the tested individual the physician needs to have the consent of the relatives whose medical information and test result the physician is seeking. This often requires some disclosure of the tested individual's medical information in the reasoning given to the family member from whom the consent is being sought. So in some cases, determining an individual's personal risk assessment requires the consent of the tested individual for some of their information to be disclosed to their relative, and the consent of the relative for their medical information and test results to be used.

So far I have discussed genetic testing for an inherited susceptibility for those individuals who have received a physician recommendation, but sometimes individuals do not present with the indicators that would result in a physician recommendation for testing. At one time this would mean that either these individuals would not get testing or that they would need to seek out testing through a private genetics laboratory. Genetic testing through a private genetics laboratory is an option for those individuals who can afford to pay for testing. However, the procedure can differ from genetic testing that is offered after a physician recommendation is made. Some private laboratories follow the same procedure, but others do not offer genetic counselling to their clients.[416]

[416] NHS Predictive Genetic Tests For Cancer, Accessed March 1st 2017 http://www.nhs.uk/Conditions/predictive-genetic-tests-cancer/Pages/Introduction.aspx.

Those individuals who are willing to seek out genetic testing without this counselling may not have the requisite information to make an informed decision about getting testing. However, it can also be the case that individuals willing to incur the cost of private genetic testing have done their own research regarding this kind of testing and have made an informed decision. Once they receive their results they can then seek out the advice from their physician in helping them to understand their potential risk. The portion of Figure 2 relating to private laboratories that include genetic counselling looks very similar to the physician recommended procedure. The main difference is that the procedure does not loop back around to a physician's recommendations if the test result is positive. These recommendations would need to be sought outside of the procedure for testing. The bottom portion of Figure 2 illustrates the steps the individual would go through if they opt for a private laboratory that does not provide genetic counselling.

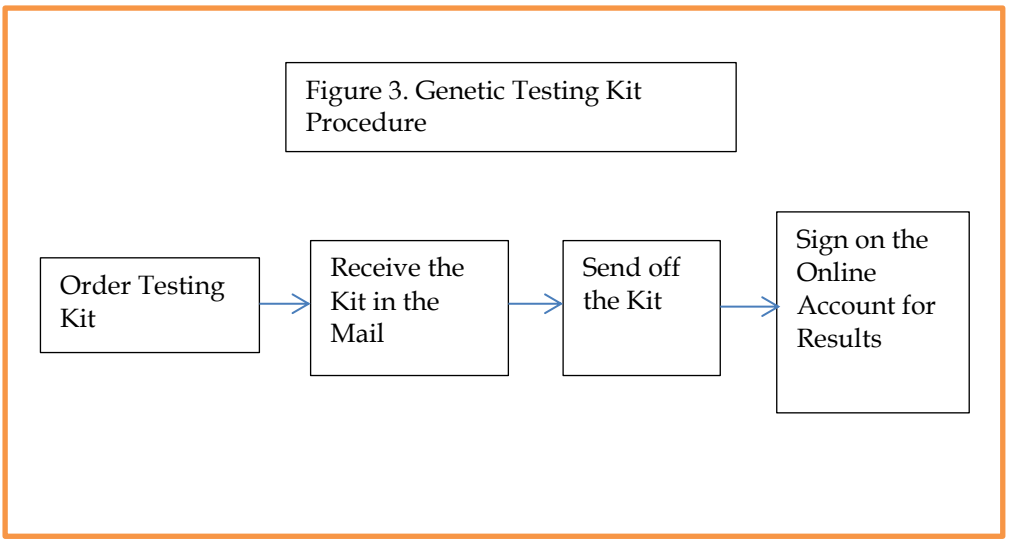


In more recent years genetic testing kits have been advertised directly to consumers. An individual can order a genetic testing kit online or through some pharmacies or drug stores and send their sample back to the company to be analysed. Their results are then available through their online account. This method of genetic testing is easily accessible and much cheaper than going to a private genetics laboratory. The uptake and availability of this kind of genetic testing differs across countries. For instance, in some countries the testing kit can be marketed in stores, while in other countries its marketing is more restricted.[417] In the United Kingdom, Superdrug started selling a genetic testing kit in-store in the spring of 2015, but has since removed the product from store and it is only available for purchase through their website.[418] There is absolutely no genetics counselling provided and the websites often have a disclaimer stating that their genetic test is not a diagnostic tool.[419]

The website provides informational videos to help individuals to understand their results. For any further clarification or if their results are a concern to them the individual would need to make an appointment with their physician. Figure 3 illustrates the steps that an individual will go through to attain their genetic test result using a genetic testing kit.

---

[417] Andalo, 2015, online.
[418] While I could not find an article detailing why the product was removed from stores the chain got a lot of criticism for stating to sell the 23andme test. One article detailing the concerns is: https://www.theguardian.com/science/2015/mar/31/superdrug-criticised-doctors-genetic-self-testing-kits Accessed December 31st 2018.
[419] https://www.23andme.com/en-gb/health/ Accessed March 4th, 2017.



Recent studies have been conducted to determine whether individuals understand the test results of their direct-to-consumer genetic testing kits. These studies suggest that individuals do understand the test results that they receive.[420] Understanding test results in these studies is measured by the individual's ability to understand the information presented and have a grasp on what it means for them. [421] So, the respondents of the study show that they understand that an inherited susceptibility means that they have an increased risk of developing cancer.[422] However, a study conducted at the University of Michigan did note that group selection may have been a factor in the level of understanding demonstrated by the participants. The study selected from individuals who had used the genetic testing kits from two different

[420] Arbor, 2015, online and Francke, Dijamco, Kiefer, Eriksson, Moiseff, Tung, and Mountain, 2013, online.
[421] The level of understanding that is being tested is not some in depth knowledge of oncology or genetics, but the general sorts of information that might be viewed as a lay understanding of what genes do or how they work.
[422] There have been studies that indicate that there is a bit of a gap between understanding risk and our ability to accurately apply that risk to ourselves. From what I have gathered from reading the studies in footnote 417 the studies were investigating the former.
One study regarding this gap is Crities and Kodis, 2012.

companies, but participants had a higher level of education and income than the general population.[423] The selection of these participants may reflect a higher level of understanding than a more reflective cross section of the general population.

Understanding the differences between what is offered with these three methods of seeking genetic testing will play a role in the discussion concerning autonomy later in this chapter. Studies concerning how well individuals understand their genetic test results demonstrate that the respondents can understand the results, but the studies do not address whether they understand the implications of the results. To date, studies looking into whether individuals understand how their test results might impact on their life, or what types of consequences genetic testing might have for them, have only been conducted with regards to the first two methods of testing discussed above. Since the provision of genetic counselling is typically included in these testing procedures these studies may have different results from testing procedures that do not involve genetic counselling. There have not yet been studies looking at how these results may differ when individuals seek out genetic testing through direct-to-consumer genetic testing kits. It is one thing to understand that there may be an increased risk of developing a disease, but another thing to understand how knowledge of this increased risk might affect your life.

[423] Arbor, 2015, online.

II – Understanding the Risk

This section is going to look at how the increased risk of having an inherited susceptibility might work, not how individual might understand that risk. An individual with an inherited susceptibility has an increased risk of developing cancer across environments.[424] This means that an individual who has an inherited susceptibility has a greater risk of developing cancer than an individual who does not have an inherited susceptibility but who makes similar lifestyle choices.[425] The average person has approximately a 30% lifetime risk of developing cancer.[426] Recent research has discovered more than 100 gene variations associated with an increased risk of developing ovarian, breast, and prostate cancer. Each of these gene variations only increases an individual's risk by a small amount, but if the individual has several of these gene variations each small increase in risk can be compounded and result in a much higher risk.[427] Precisely how this increased risk is affected by environment can determine how beneficial it might be for an individual to maintain a healthy lifestyle. By maintaining a healthy lifestyle an individual can reduce their personal risk of developing cancer. However, this reduction in risk will not make their risk comparable to that of an individual without an inherited susceptibility making the same lifestyle choices.

---

[424] Environments in this sense refer to variables being considered. So in this instance 'environment' refers not just to the physical location that the individual inhabits, but also lifestyles.
[425] Tabery, 2009, 30.
[426] Suthers, 2008, 33.
[427] "Predictive Genetic Tests for Cancer" Accessed March 1st 2017 http://www.nhs.uk/Conditions/predictive-genetic-tests-cancer/Pages/Introduction.aspx

My research has indicated that an inherited susceptibility increases an individual's risk of developing cancer across environments,[428] but it has been unclear how this increased risk looks across environments. For instance, does an individual with an inherited susceptibility incur the same increase of risk across different lifestyles as an individual without an inherited susceptibility, or does the individual's risk of developing cancer increase more than those without an inherited susceptibility?

How the individual's risk increases across different lifestyle choices may show that the individual has very strong reasons for maintaining a healthy lifestyle, because doing so would cause a large reduction in their personal risk. Alternatively, it could be that the individual with an inherited susceptibility may gain a very low reduction in risk by maintaining a healthy lifestyle. This low reduction in risk may not provide the individual with strong enough reasons for them to make a change to their lifestyle choices. Maintaining a healthy lifestyle is recommended during the post-testing genetic counselling session as a means of reducing the risk of developing cancer. While the reduction of risk may provide an individual with reasons for changing their lifestyle, risk is not the only reason that people may choose to make different lifestyle choices. There are many complex and differing reasons that people make any number of lifestyle choices.

In this section I will discuss how lifestyle choices may increase the risk of developing cancer for those with an inherited susceptibility to cancer compared to those without this risk. It is unclear how much lifestyle choices increase the risk of individuals who have an inherited susceptibility to cancer,

[428] Tabery, 2009, 30.

but cancer is a multifactorial disease, so I think that it is worthwhile to include this type of discussion. Particularly when we are thinking about how a reduction in risk might give an individual reasons to motivate a change in their lifestyle choices. The main point of the following discussion is that it does not follow from the fact that someone has an inherited susceptibility that the impact of lifestyle choices on risk is the same as it would be for someone without an inherited susceptibility. In principle, lifestyle choices could make more, the same, or less difference than they would for someone without an inherited susceptibility.

It might be the case that an individual with an inherited susceptibility may experience the same increase in risk as an individual without this kind of susceptibility if both individuals live equally unhealthy lifestyles. Say engaging in a moderately healthy lifestyle increase each individuals level of risk by 5%, so their risk has increased by the same degree even though their starting level of risk is different. This would mean that they can both decrease their risk by the same amount if they change their lifestyle choices. This reduction in risk may give both individuals equally strong reasons to make changes in their lifestyle choices.

If the an inherited susceptibility increases an individual's risk in a higher degree than those who do not have an inherited susceptibility, then one can have stronger reasons to motivate a change in lifestyle choices than those who do not have an inherited susceptibility. Say an individual with an inherited susceptibility experiences a 10% increase in their risk when living a moderately healthy lifestyle, while the individual without an inherited susceptibility only experiences a 5% increase in risk from making the same

lifestyle choices. This would mean that the individual with the inherited susceptibility would experience a larger reduction of risk from making healthier lifestyle choices. This greater reduction in risk could provide the individual with inherited susceptibility stronger reasons to motivate different lifestyle choices than the individual without an inherited susceptibility.

However, perhaps lifestyle choices do not increase the level of risk by very much for those with an inherited susceptibility. Maybe their baseline level of risk is high, but their lifestyle choices do not have as much impact on their level of risk. So, if both individuals live a moderately healthy lifestyle the individual with the inherited susceptibility has an increase in their risk by 2%, while the individual without the inherited susceptibility has an increased risk of 5%. With a lower reduction of risk, than the individual without the inherited susceptibility, the individual with an inherited susceptibility may have much weaker reason to motivate a change in their lifestyle choices.

Lifestyle choices that can have an impact on the individual's risk of developing cancer are not limited to diet, exercise, and habits. Lifestyle choices such as careers, recreational activities, and where we choose to live can also make an impact on our risk of developing cancer.[430] For instance, careers involving chemicals associated with causing cancer, or involving working with equipment that emits radiation can increase an individual's risk of developing cancer. Formaldehyde is one such chemical. This chemical is used to store specimens, embalm humans, and in a myriad of other products such as pressed wood. Most of us come into contact with small

[430] It is important to note that not everyone can choose where they live, or the environment in which they dwell. This issue is discussed in more detail in section V.VII.

amounts of formaldehyde every day from exposure to car exhaust fumes and from cooking using a gas stove.[431] After several studies linking increased exposure to formaldehyde with incidences of certain types of cancers, governing bodies introduced legislation limiting the amount of formaldehyde that workers can be exposed to in any given day.[432] Careers that involve frequent exposure to formaldehyde include some healthcare professions, laboratory technicians, mortuary employees, and some types of industrial workers.[433]

Careers and other lifestyle choices need to be taken into consideration when we are thinking about reducing one's risk to developing cancer. Some of these lifestyle choices may be easier to change than others. Lifestyle choices like these will be considered again later in the chapter when discussing the impact that genetic testing can have on the tested individual's well-being.

III – Reasons for Seeking Genetic Testing

Genetic testing can tell us things about ourselves, our possible future health, and any future children that we might have. Because of this, genetic testing can be an attractive opportunity for one to gain knowledge about oneself. There can be several reasons that might motivate people to seek out genetic testing. These different reasons for testing can play a role in determining how one might go about getting tested.

---

[431] "Formaldehyde" Accessed March 4th 2017 https://www.cancer.gov/about-cancer/causes-prevention/risk/substances/formaldehyde/formaldehyde-fact-sheet
[432] "Formaldehyde" Accessed March 4th 2017 https://www.cancer.gov/about-cancer/causes-prevention/risk/substances/formaldehyde/formaldehyde-fact-sheet
[433] "Formaldehyde" Accessed March 4th 2017 https://www.cancer.gov/about-cancer/causes-prevention/risk/substances/formaldehyde/formaldehyde-fact-sheet

Cancer has touched many lives, and some more than others. Some families have a high frequency of cancer among their relatives. For these individuals, seeking out answers as to why so many of their loved ones have developed cancer can be appealing. A family history of cancer can cause an individual to worry about developing cancer. Breast cancer is one of the most highly publicised cancers and the potential genetic component to this cancer is widely known.[434] Having a relative with a positive test result can provide other family members with reasons that motivate them to seek testing. The health related reasons presented here can motivate individuals who would like to get genetic testing, and possibly those who do not, to seek out a physician's recommendation for testing or reassurance about their decision not to be tested. For those individuals who do not demonstrate the indicators that physicians use for making recommendations, the lack of recommendation may not alleviate their worries and they may seek out testing through private genetics laboratories.

Some individuals are naturally curious, and even without a family history of cancer they may just want to know whether they have an inherited susceptibility. They too may feel that knowing this is important to their future health because they can do something to try to avoid developing cancer. These individuals may seek out this kind of testing simply for the sake of this knowledge. Other individuals may have general worries or anxieties about their future health. Seeking out this information can provide them with

[434] I am not overlooking men in this instance. Men also get breast cancer; it is just less common than in women. The studies that I have read in this area often look at families with generations of women with breast cancer and often refer to the men of these families as carriers of the genes. If these studies did include families with men who had been diagnosed with breast cancer they did not indicate this.

comfort, or help them to make appropriate lifestyle changes to reduce their personal risk.

However, some may think that the knowledge about whether they have an inherited susceptibility is only secondary. They cannot change their possible inherited susceptibility, but they can try to create a child who is free from an inherited susceptibility. The concern of passing an inherited susceptibility to future children can apply to individuals with and without a family history of cancer. Individuals with no family history of cancer may be needlessly worried about an inherited susceptibility, but for those with a family history of cancer this worry may be warranted.

In section I.II discussed different means of procuring genetic testing. Different reasons for seeking out genetic testing may also influence the means by which they attain it. An individual with a family history of cancer, or who is a carer for a relative who has cancer, or who has discovered that a relative has an inherited susceptibility, may be more likely to approach their physician for a recommendation. Individuals who have general health worries or anxieties may also seek out a recommendation from their physician. Without the indicators that physicians look for the request for a recommendation will likely be refused. If the individual is sufficiently worried the refusal may motivate them to seek out genetic testing which they can purchase. These individuals may also be likely to pay for private testing to alleviate their worries and anxieties. At the same time, they may find that the availability of the test online would be a convenient way of receiving testing. Individuals who are curious may not be willing to pay for an expensive private test, so they may be more likely to opt for a genetic testing kit. Individuals seeking

testing to make reproductive choices may see going through a private genetics laboratory as a viable means of getting tested, but they may also opt for purchasing a testing kit online.

IV - What are the Benefits?

When thinking about how people might respond to this type of testing and what kinds of benefits people might experience from testing there can be contributing factors that are very individual to the person in question. An individual's personality and outlook can play a big role in whether they experience benefits. If the individual has an optimistic disposition, or tends to see a silver lining in events, then they may be more likely to experience these benefits. If an individual is typically pragmatic, then again they may experience some combination of the benefits discussed below. In the presentation of the following benefits, and also the disadvantages, it is important to remember that individuals can experience some, all, or a combination of what follows. The lists provided in the next two sections are not meant to be exhaustive.

IV.I – The Advantages of Knowing

The knowledge that one has or does not have an inherited susceptibility can be beneficial to the screened individual, and the benefits might be dependent on the type of value that knowing has. Knowing can be valuable in several ways: epistemic, moral, social, and pragmatic. An individual may benefit from knowing that their test results because they value having this knowledge, whichever way the results turn out. An individual may feel that knowing has some moral value. They may believe that they have some moral

responsibility towards potential future children to take measures to reduce their risk of passing on an inherited susceptibility.[435] The knowledge can be valued for pragmatic reasons, the individual may feel that to make decisions that are in their best interest or to make appropriately informed decisions they need to know what their test results are. This ties in with the capacities constitutive of autonomy, in particular the empirical reasoning and the normative principle capacities discussed in chapter three. However, it is important to remember that we are not particularly good at utilising our decision-making skills. This was highlighted in chapter three and will be discussed more below. These different ways of valuing knowing this information may come into conflict, and some of this will be addressed in the following discussions.

Knowing that one does not have an inherited susceptibility can alleviate an individual's worries or anxieties about being at an increased risk of developing cancer. An individual with a family history of cancer may feel more at ease knowing that they have the same level risk of developing cancer as the general population. Knowing that one does have an inherited susceptibility can help to make different lifestyle choices. This knowledge can provide them with strong reasons to motivate a change in lifestyle. The individual may also feel like they can make changes that can help them to manage their risk more effectively.

[435] This will be discussed in more detail in the two sections about reproductive choices.

IV.II – Career and Hobbies

Knowing that one is at an increased risk of developing cancer may give the individual strong reasons for making healthy lifestyle choices and can provide the extra motivation to make changes that they might not have made otherwise. This knowledge may provide the individual with reasons that motivate them to re-evaluate their current lifestyle choices, or to learn more about things in their life that may be putting them at an elevated risk of developing cancer. These lifestyle choices may range from small scale choices; say about food or hobbies, to large scale choices, like careers or places they live. For instance, the individual may take a more in depth look at their hobbies or recreational habits, paying more attention to warning labels. For example, suppose that an individual paints in their spare time, or they may be a professional artist. Painting often involves the use of different chemicals or other supplies. Some painting supplies have been found to have links to developing cancer. One example of this is cadmium red oil paints; some brands of this paint have been banned in some states in the United States because of the links to causing cancer. There is a warning label to this effect on tubes of this colour of paint. The individual may decide to switch to a different type of paint, or avoid using a particular hue. Cycling is another example, exercise is often viewed as something that contributes to a healthy lifestyle, but exercise that is frequently enjoyed outdoors may pose special kinds of consideration. If one resides in a large urban area extended time outdoors in polluted air may pose some health risks, particularly if the individual has an inherited susceptibility, since pollution typically includes

carcinogens. The individual may choose to change their preferred method of exercise, move their exercise indoors, or only go cycling on vacation.

The individual may look at different career options; it can be particularly useful to find out about their inherited susceptibility before undergoing career training; or they may move to a location with better air quality. The individual may also deem that they enjoy their career, hobbies, and home enough to accept the elevation in risk that these activities or locations may impose.

IV.III – Reproductive Choices

The individual may accept their elevated risk, but may not wish to pass this part of themselves on to their future offspring. Knowing prior to creating a family can alter how the individual goes about producing that family. Their desire to have children may remain unaltered, but the method they use for attaining this desire may change. The individual could choose to use preimplantation genetic screening (PGS), or they may decide to adopt. In some places individuals with an inherited susceptibility are offered PGS through their healthcare system.[436]

A study conducted by Catherine Dekeuwer and Simone Bateman interviewed individuals with an inherited susceptibility regarding their reproductive choices.[437] This study found that many of the respondents felt that PGS should be available to those with an inherited susceptibility, but they

---

[436] Dekeuwer and Bateman, 2013, 231.
The respondents in this study were comprised of nineteen women and one man who were identified as carriers for either the BRCA1 or BRCA2 genes.
[437] This study interviewed 19 women and one man who were carriers of BRCA 1/2 mutations.

themselves were unlikely to use it.[438] The researchers found that "discovering one's carrier status as such does not seem to have a systematic effect on a person's decision to have a(nother) child."[439] The individual and their partner could also determine that a 50% risk of passing on the inherited susceptibility is an acceptable level of risk and conceive a child in the traditional manner. Reproductive options for individuals who have tested positive for an inherited susceptibility are discussed in genetic counselling sessions. This discussion is one of the benefits of genetic counselling.

IV.IV – Risk, Surveillance, and Prevention

Another benefit to seeking this type of testing is that the individual can receive an accurate risk assessment. They can learn their relative level of risk of developing cancer in the future. Knowing this risk, they may choose to take up the offer of a frequent screening regime. The early detection of cancer has clear health benefits for the patient. Early detection generally leads to a better level of health after treatment and a longer life expectancy.

There may be other preventative measures that the individual may seek out. A woman may choose to have a prophylactic mastectomy or prophylactic ovariectomy. The recommendation of preventative surgery varies, and the efficiency of this type of preventative measure has been debated. For some cancers, such as breast and prostate cancer, the suggestion of chemoprevention may be offered. However, chemoprevention has had mixed

[438] Dekeuwer and Bateman, 2013, 241.
[439] Dekeuwer and Bateman, 2013, 238.

results and the efficiency of this type of treatment is also debated.[440] The individual may also choose self-check for some cancers, and may develop a heightened awareness of their own bodies and of the normal fluctuations and bodily sensations that they experience on a daily basis that had previously gone unnoticed. In this sense the individual may have an increased sense of embodiment and awareness of what it is like to be them. These are all benefits that one might gain from this type of testing.

IV.V – Family Relations

Testing of this kind can also strengthen familial relationships. The tested individual may choose to disclose the results of their test to family members who may also be at risk of having an inherited susceptibility. Those family members who have an inherited susceptibility may come together in a supportive way to share their general worries or concerns about developing cancer. Relatives may share in the screening experience and have people that they can talk to who understand the worries and apprehension they experience leading up to their scheduled screening and waiting for their results. Having individuals that they are close to and in a similar situation as them can reduce their general worries and make them feel like they belong. This can reduce the feeling of isolation that the individual may experience from being at an increased risk of developing cancer. Those individuals who have tested negative for an inherited susceptibility may feel relief, and sharing this information may alleviate some of their relatives' concern for them. Their carrier parent may be absolved of feelings of guilt or a sense of

[440] An example of can be found in the following exchange. Justman, 2011b, 21-25; Huang and Baum, 2011, 27-29; Justman, 2011a, W1-2.

responsibility they may have been carrying knowing that they could have passed their inherited susceptibility on to their child.

IV.VI – Perception by Others

In the event that an individual with an inherited susceptibility develops cancer, others may attribute their developing cancer to their genetics and not to their lifestyle choices. With some cancers one might be inclined to assign blame or responsibility to the individual's part in developing cancer. We see this sometimes with individuals who smoke and later develop lung cancer. We sometimes attribute the situation that someone finds themselves in to the actions of the person as an explanation for their situation, without realising that this is what we are doing, but if the individual has not acted in a way that we can see as causing or deserving of the situation, then we are more likely to think that their finding themselves in that situation was due to something that that was out of their control.[441] Assigning blame or responsibility in this way may result in the individual with an inherited susceptibility receiving sympathy because their developing cancer had a genetic component and so was in some sense out of their control.

These benefits may have a positive impact on the tested individual's well-being and may influence their ability to make more informed decisions in their life. This section has indicated some of the possible benefits of genetic testing and how these benefits can have a positive impact on the tested individual's well-being and autonomy. The next section will consider some of

[441] Sherman, 2014, online.

the possible negative impacts on well-being and autonomy that this type of testing can have. The next section follows a similar structure to this section.

V – What are the Costs?

This following section will look at some of the ways that finding out about one's inherited susceptibility might negatively impact on one's well-being and autonomy. Like with the benefits, the individual's disposition or outlook on life might influence how they perceive their results. Again it is important to note that they may experience any number of these costs or a combination of both benefits and costs. The individual's perspective or disposition can influence how they use this information in their decision-making and how they exercise their autonomy.

V.I – The Disadvantages of Knowing

Discovering that one does not have an inherited susceptibility can make the person feel as though they dodged a bullet in a sense. This can have a negative impact on their well-being because they may feel that they can live whatever lifestyle they wish, which may result in poor lifestyle choices.[442] On the opposite end of the scale, learning that one has an inherited susceptibility may cause one to have a nihilistic perspective on their future.[443] As these

[442]"Direct-to-consumer genetic testing kits", *Harvard Health Publications: Harvard Women's Health Watch*, Harvard Medical School Published: September 2010, Accessed February 23rd 2017 http://www.health.harvard.edu/newsletter_article/direct-to-consumer-genetic-testing-kits

[443]It was noted in this study that one's response to the knowledge they acquire can be influenced by whether they were optimistic or nihilistic prior to testing, but that testing can change one's perspective.
"Direct-to-consumer genetic testing kits", *Harvard Health Publications: Harvard Women's Health Watch*, Harvard Medical School Published: September 2010, Accessed February 23rd 2017 http://www.health.harvard.edu/newsletter_article/direct-to-consumer-genetic-testing-kits

responses are both extremes, there will also be those individuals who may see their inherited susceptibility as something that will limit their future opportunities, but not something that is inevitable or completely eliminates any future opportunities. It is likely that the majority of people who experience a negative impact on their well-being from this knowledge will fall into this middle range.[444] Gaining the knowledge that one has an inherited susceptibility may result in altering the individual's perception of the range of their future opportunities in a way that can be life limiting.

The different types of value that an individual may assign to knowing can come into tension here. An individual may think that they having this knowledge involves some extra moral responsibility on their part, potentially to future children, or other family members. Knowing one's test results may in putting strain on close relationships, for instance one might feel obligated to share their results with family members or that they have some extra obligation to their children based on passing the gene variants on.[445] They may decide after being tested that knowing their results is quite distressing, or makes it more difficult to make decisions, so there may be some pragmatic costs to knowing.

V.II – Career and Hobbies

Lifestyle choices involving careers and hobbies may also be altered with this information. Individuals may give up on activities that they enjoy for fear

[444] Statistically when you have two extremes you will find most of your sample in the middle areas. At least, in a lot of scientific and psychological studies results typically form a bell curve. It also seems likely that if the range has extreme optimism on one side and nihilism on the other that you are likely to find most people somewhere between these two.
[445] Some of these issues will be discussed in further detail below.

that those activities may increase their risk of developing cancer. In the previous section painting was discussed as a possible hobby or career choice that an individual may have and may choose to alter or to continue participating in. It could also be the case that, although the individual enjoys painting and finds the activity to be nurturing in some way, the fear of continuing the activity and perhaps increasing their risk of developing cancer can also influence the individual to give up on the activity. Discovering that something that you identify with and enjoy can increase your risk of developing a potentially life threatening disease can be devastating.[446] Similar examples can be used when thinking about potential career options, particularly if the individual has dedicated years of study to achieve the required credentials to have the career that they do. For example, many of the occupations highlighted earlier when discussing formaldehyde require some level of higher education to be qualified for the position. The perceived restriction on their options may not be an issue for the some tested individual since they had not made any firm decisions as of yet or dedicated as much time to a career that no longer seems viable to them.

V.III – Reproductive Choices

The achievement of some desires and ambitions may appear to the individual as unattainable now that they know more about their potential future health. For instance, with a positive test result the individual may feel that the option of having a child is now closed to them, but in actuality this option only appears to be closed to them because there are reproductive options available.

[446] Carel, 2008, 31-32. While this is about changes regarding a physical aliment I think that there are parallels here.

The information that they receive during genetic counselling about reproductive options and the likelihood that they will pass on the inherited susceptibility to future offspring can be daunting. Some of the respondents in Dekeuwer and Bateman's study reported that they thought it was not morally acceptable to knowingly take the risk of passing on an inherited susceptibility to future children.[447] The moral permissibility of knowingly passing on potentially harmful genetic material to one's offspring is a complex issue. This issue highlights several philosophical problems regarding future people and whether you can harm an individual who does not yet exist. This question also brings to light some of the main points of the non-identity problem: can the individual you create claim that you have harmed them if that particular individual would not exist had you made a different decision?[448] This can also raise issues concerning parental obligation and the nature of that obligation, or the child's right to an open future.[449] These questions are complex and cannot be addressed adequately in the space provided, but it is important that they are acknowledged.

Some individuals who value having a child of their own may consider a 50% risk of transmitting an inherited susceptibility to their children to be too great. These individuals may still have the opportunity to use PGS, but this is quite expensive in cases when the procedure is not offered through the healthcare system. The individual may also have reservations about using this method to have a child because several embryos are created then tested

[447] Dekeuwer and Bateman, 2013, 239.
[448] *The Stanford Encyclopedia of Philosophy* s.v. "The Nonidentity Problem" by M.A. Roberts, Accessed on March 1st 2017 https://plato.stanford.edu/entries/nonidentity-problem/
[449] Refer to Prusak, 2013 for discussions on parental obligation.

for the gene variations associated with an inherited susceptibility. The embryos free from the gene variations will be implanted while the others are discarded.

An individual who believes that it is morally unacceptable to knowingly pass on an inherited susceptibility and has reservations about the acceptability of discarding embryos containing these gene variants will have to forgo having children that are genetically related to them. This can be a devastating blow to an individual or a couple. Limitations in one's reproductive options can also have an impact on one's perception of whether one is a viable potential partner for some person in the future.

V.IV – Risk, Surveillance, and Prevention

Surveillance or a frequent screening regime is often advised for individuals with an inherited susceptibility. However, some individuals with a family history of cancer will avoid this kind of screening.[450] Frequent screening for cancer comes with its own set of anxieties and worries. Worrying begins as the scheduled test is approaching then extends until the individual receives the results. Once the results are in they may alleviate some of the worry until the next test. The relief felt after each subsequent test in a frequent screening cycle may not completely alleviate the worry that the individual has when waiting for the tests and results. Concerns about what they might find next time may be ever present in the mind of an individual undergoing frequent screening and surveillance.[451]

[450] Parker, 1995, 1995, 329.
[451] Carel, 2008, 37-38.

This cycle of worry and anxiety can have a negative impact on the individual's physical and psychological health. Investigations as to the impact of health anxiety and possible treatments are the topic of current research in healthcare and psychology.[452] Further, frequent exposure to cortisol, a hormone excreted when stressed, has been linked with digestive problems, such as ulcers and acid reflux, and a reduction in the functioning of the immune system. Continuous exposure can result in a permanent reduction in the functioning in the immune system.[453] Surveillance and frequent screening can also alter the relationship that the individual has with their body. They may feel that they are simply waiting for the day that their body betrays them and develops cancer.[454]

There are few reliable preventative treatments available for cancer. In the previous section I mentioned chemoprevention and the mixed views on its efficiency. Often chemoprevention is accompanied by long lasting or permanent side-effects which can be difficult for an individual to cope with, particularly if the efficiency of the treatment is suspect.[455] For some cancers like breast and ovarian cancer an individual may seek out preventative surgery. Women can reduce their risk of developing cancer by cutting off or removing parts of their bodies. The parts of their bodies that they can remove to reduce their risk are parts of their bodies that are often intertwined with their self-esteem and personal identity. This is discussed in several papers

[452] One such study is currently being conducted at the University of Nottingham. The principle investigator for this study is Professor Richard Morris.
[453] Choi, Fauce, and Effos, 2008, online.
[454] This description of the self/body relationship is highlighted in studies conducted across disciplines and in biographies written by individuals through their illness. The feeling that the body has or will betray them is not unique to cancer, or those living in the shadow of a family medical history of cancer.
[455] Justman, 2011b, 23-24.

about testing for an inherited susceptibility to breast cancer.[456] Lisa S. Park says that, to women "their breast may appear to them as time bombs that they desperately want to diffuse, but do not want to be rid of."[457] Some may view a woman's reluctance to do everything she can to reduce her risk of developing cancer as not doing enough or being negligent in her healthcare.[458]

Questions of personal identity in illness and the relationship between the self and the body have been addressed across several disciplines. They arise in areas such as medical sociology, medicine, nursing, psychology, and philosophy. The research in this area looks at the duality of the self.[459] There is the sense that the self is one thing; the combination of the self that contains thoughts and characteristics that make each individual unique and the body of which it is housed in and intimately intertwined with. The body makes for a clear boundary between what is the self and what is the other. However, in illness this wholeness, the self being comprised of both self and body, can come apart. The individual can begin to perceive their body as having betrayed or trapped them. The body can become a threat. Ultimately, this may alienate one part of the self from the other.[460] While many of the studies available look closely at the relationship between the individual's body and their sense of self in sickness, I think that these issues could arise in individuals who have an inherited susceptibility. Instead of waiting for the

[456] Press, Fishman, and Koenig, 2000, 245-246, and Parker, 1995, 325-329.
[457] Parker, 1995, 329.
[458] Parker, 1995, 320 .
[459] Charmaz and Rosenfeld, 2009, 318.
[460] The perception that the body has betrayed the individual or is a threat is a reoccurring theme in Parker, 1995; Carel, 2008; Wenger, 2013, 389-399; Piot-Ziegler, Sassi, Raffoul and Delaloye, 2010, 479-510; and D'agincourt-Canning, 2010, 139-156, to name a few sources.

next limitation that their body may place on them, they are waiting for it to turn against them – much like Park's ticking time bomb expression.

Just as illness might change and shape an individual in ways they might not have thought that they would change, altering values and goals, so too can the knowledge that one has an inherited susceptibility. I think that it can also alter their identity in certain ways, by changing values that they may hold core to their identity, or causing them to view parts of themselves as a threat to aspects of their identity. Some women who have an inherited susceptibility to breast or ovarian cancer may see the parts of themselves that are biologically tied to their sex and gender identity as suddenly being dangerous to them. Men may feel that their body is a threat to their gender identity in the sense that prostate cancer and treatments for it can cause erectile dysfunction, which could be quite damaging to their sense of masculinity. This sense that parts of yourself are a threat to who you are can make the individual feel alienated from themselves in a way that can be quite damaging. This is different from the way that an individual can feel alienated from a part of themselves in sickness because it begins before the development of a disease. Some individuals never develop cancer, but their fear that their body is a threat or might betray them and this separation between their self and their body can still be present, shaping or reshaping who they are.

V.V – Family Relations

An inherited susceptibility is shared among family members—not all of one's relatives, but some number of them. In a genetic counselling session the

counsellor will discuss how testing for an inherited susceptibility can affect the individual's relationship with their family. At this time they will also discuss whether the individual would like to disclose their test results to those of their relatives who may also share an inherited susceptibility. Many individuals opt for the disclosure of their positive test result to their family, since they feel that in a sense the information isn't just theirs, but belongs to their relatives as well.[461] The decision, by the tested individual, not to disclose this information to their relatives can result in the relatives developing feelings of betrayal if or when the relatives find out that the individual knew that they potentially shared an inherited susceptibility and the relatives may view the nondisclosure as being the result of the tested individual selfishly keeping the information, which isn't entirely theirs alone, to their self.[462] Confidentiality issues may arise here because the test results are in some sense the tested individual's, but also in some sense belong to the family. There is a certain amount of sharing in each person's genome.

In the previous section I discussed how the knowledge that one has inherited susceptibility may strengthen their relationship with their family and their family may be a source of support and comfort. This may not always be the case. Some family members may feel that the individual is not making the appropriate lifestyle changes, or taking the appropriate preventative measures to reduce their risk. The voicing of these concerns may create

[461] Dheensa, Fenwick, and Lucassen, 2016, 175-176.
[462] Dheensa, Fenwick and Lucassen, 2016, 175-176. This study interviewed 33 patients who had recently been seen for hereditary cancers and cardiac conditions. Interviews were structured around general, open-ended, non-leading questions.

tension between family members, causing the tested individual to feel isolated or even causing them to sever ties with their family.[463]

V.VI – Perception by Others

For those individuals who do develop cancer, the perception of their illness can have a negative impact on the individual's well-being. One's social relationships can become difficult or strained and public perceptions or stereotypes about illness can make the individual vulnerable.[464] The individual who has knowledge of their inherited susceptibility may be more likely to be blamed for developing cancer. People may feel that they have not done enough to reduce their risk of developing cancer. They didn't make enough of an effort to make the appropriate lifestyle changes or preventative measures that would have reduced their risk.[465] Victim blaming can be problematic because it assigns more blame to the individual for their situation than may be warranted.

This type of victim blaming occurs when people are attempting to make sense of bad things that happen in the world. By blaming the victim people can reassure themselves that the same kind of thing will be unlikely to happen to them, because they did not act in such a way as to cause the situation to occur. In this case, the situation or bad thing that people want to avoid is developing cancer. The combination of pointing to character flaws and blame helps to alleviate some of the pressure or loss of control that those around the

[463] Parker, 1995, 320.
[464] Carel, 2008, 50-53.
[465] Parker, 1995, 320 and Press, Fishman, and Koenig, 2000, 245.

individual may feel.[466] If the individual is to blame or has some character flaws that contributed to their developing cancer, then their relatives who also have an inherited susceptibility may feel that they can avoid the same misfortune because they do not share in those flaws or have not engaged in the same kind of blameworthy activities. The evaluation of the individual's life choices could fall under more scrutiny than those of an individual without an inherited susceptibility.

The knowledge of an inherited susceptibility can also contribute to the stigmatization of those types of cancers, particularly for those people with an inherited susceptibility to them. We see something similar with lung cancer and smoking. Smoking is not the only thing that causes lung cancer to develop, but people are quick to blame an individual who smokes for their cancer.[467] A similar position can be taken for those who know that they have an inherited susceptibility. With the knowledge that an individual has an inherited susceptibility there are a number of things that that individual can do to mitigate that increased risk, like making appropriate lifestyle changes and engaging in frequent screening. These changes in some ways can be seen as making the development of cancer preventable. By not making appropriate lifestyle changes the individual is engaging in some health risking behaviours and these behaviours may be perceived as in some ways riskier for the individual with an inherited susceptibility than they are for those without. So, these individuals are seen as more to blame for their development of cancer because they engaged in these health risking activities.

[466] Haynes and Olson, 2006, 665.
[467] Bresnahan, Silk and Zhuang, 2013, E133.

However, while some amount of blame may be appropriate because there is a sense in which the individual is responsible for their health, some kinds of blame are not. We all have some responsibility for our health, but there are still aspects about our health that may be out of our control. The view that these cancers are preventable and the result of risky health behaviours can contribute to the stigmatization of these cancers and to inappropriate responses, namely victim blaming and prejudice. What is needed is more awareness and understanding about the genetic links to these cancers, along with a shift in public understanding. It has been proposed that awareness of the stigmatization and prejudices associated with certain health conditions is needed for medical professionals.[468] The awareness of stigmatization and prejudices associated with certain health conditions can help to reduce victim blaming and I think the same can apply to genetically linked cancers.

I think that encouraging this type of understanding in those individuals who have an inherited susceptibility can help us to avoid victim blaming, or at least to reduce its impact. Incorporating some of the same techniques for reducing stigma and making people aware of the destructive power that it can have into genetic counselling sessions would be very beneficial for the individuals who are undergoing genetic testing and their families. Reducing the perception that they could have done more, or didn't do enough to avoid developing cancer, and reducing the blame that accompanies this perception, can help to reduce the negative impact that this kind of blaming can have on the individual who has suddenly become a patient. This is not to say that they bear no responsibility for their health or any decisions that could have

[468]Bresnahan , Silk and Zhuang, 2013, E137.

contributed to their developing cancer, but that some of the blame may be misplaced. Poor health choices can contribute to the development of cancer, but they are not necessarily the whole story and this is an important point to remember.

V.VII – Perception of One's Environment

The knowledge that one has an inherited susceptibility can influence how one perceives and interacts with one's environment. When one typically interacts with their environment there is a homelike quality and the knowledge that on has an inherited susceptibility can alter this perception. This alteration mirrors the kind of change in perception of one's environment that is experienced in illness. When one becomes ill parts of their environment that were taken for granted before become challenges, movements through one's environment require planning.[469] With an inherited susceptibility one's environment can shift from being benign to being potentially or unavoidably risky. The individual may become acutely aware of the potential environmental factors that are associated with causing cancer—like carcinogens in the air, exposure to formaldehyde on a daily basis, and chemicals that are added to foods. Some of these things an individual can aim to avoid, by reading food packaging and avoiding purchasing food that may contain certain ingredients. However, some of these environmental factors are harder to avoid—like car exhaust fumes, air pollution, and exposure to formaldehyde. Formaldehyde is found in building supplies in our homes and emitted when we use a gas or wood burning stove. The quantities are small and studies suggest that such minimal exposure will not have any adverse

[469] Carel, 2008, 34-35.

effects on the health of most people.[470] However, the individual who perceives their environment as potentially full of things that may increase their risk of developing cancer may not be reassured by these findings.

These worries may be increased or more strongly felt by an individual who is more financially limited. An individual with less access to financial freedom may find their control over their exposure to environmental factors to be more limited than an individual with more financial freedom. Both individuals may face similar limitations when their job opportunities are focused in urban settings where the air quality may be worse than in other places, but individuals with more financial freedom may be more likely to have control over where they live in these areas. They may be able to control what types of materials are used in their home, like switching from a gas or wood burning stove to an electric stove. Both individuals may be equally worried about their environmental exposure, but only one can take action to attempt to alleviate or reduce these worries.

This section has outlined ways that the knowledge gained from genetic testing can negatively impact on the tested individual's well-being and autonomy. Individuals may experience only some or a combination of the positive or negative impacts on their well-being and autonomy outlined in this section and the previous section. These two sections were a mirror of one another for all of the subsections, except this last one. Subsection V.VII does not have a corresponding subsection in section IV because if there are changes to one's perception of their environment resulting from their genetic

[470] "Formaldehyde" https://www.cancer.gov/about-cancer/causes-prevention/risk/substances/formaldehyde/formaldehyde-fact-sheet

test, these are likely to be negative; this is so particularly if the individual cannot change their exposure to possible risks in their environment.

VI – Respecting Autonomy: What does it mean? Whose should we be respecting?

Genetic testing can tell us each a lot about our possible future health, but it can also indirectly tell us about our relatives' possible future health. However, without further testing, we cannot know which relatives share in the same future health risks as the tested individual. Therefore, the information that we receive through genetic testing is not solely about ourselves. At the beginning of this chapter I highlighted that these concerns for relatives could present some difficulties for respecting the autonomy of those involved. For instance, in section II concerns about the requirement for the consent of relatives and the tested individual were highlighted as being important for creating an accurate risk assessment. Sections IV and V highlighted worries about whom the information provided by the results of the test belongs to. In this section I will address these issues along with the question of what it means to respect autonomy in this type of situation. Genetic testing for an inherited susceptibility falls squarely in the types of situations that L. A. Paul argues are transformative experiences. According to Paul, these types of situations cause problems for the rational decision-making procedure that we would expect of autonomous decision-making. So, how do we ensure that we are respecting the individual's autonomy when they choose to undergo genetic testing for an inherited susceptibility? I will argue that the best way for us to respect the individual's autonomy is through

ensuring that they have the opportunity to receive pre-testing genetic counselling.

VI.I – Whose Results are They?

In section four and five I discussed how an individual's test result reveals information about their own inherited susceptibility, but also that of some number of their relatives. In one sense the results are the individual's, but in another sense they are also their relatives'. In the case of physician recommended testing the information needed to attain the recommendation includes detailed information about other members of the family. Individuals' medical histories are confidential and they can choose to accommodate or refuse a request for this information. To acquire a physician recommendation the individual seeking testing requires their family members' medical history. The medical histories required for a physician recommendation are not as detailed as those required for an accurate risk assessment, but the rules of confidentiality apply.

As I have also discussed, during the pre-testing genetic counselling session the individual is informed of how their test result may impact on their relationship with their relatives and asked whether they would like to disclose their test results if they come back as positive. The impact that the individual's decision whether to disclose their results or not can have on their relationship with their relatives is also discussed. However, whether the individual's relatives' responses are warranted may depend on who the results belong to.

If the results belong to the individual alone, then feelings of betrayal or anger towards the individual's refusal to disclose their test results may not be warranted. On the other hand, if the results belong to the family in general the relative's response can be warranted. The decision to disclose or not also comes up against competing claims of the individuals involved. Adhering to the tested individual's decision to disclose or to withhold their test results involves respecting their autonomy, while it can also be in their relatives' best interests to be informed of their potential risk of having inherited a susceptibility to cancer. However, it may be that the tested individual has opted not to disclose their test result to particular relatives because they believe that the knowledge of a potential risk may be harmful to that individual.[471] In this instance question then becomes which would cause more harm: the knowledge that they may have an inherited susceptibility and should be getting tested, or not being tested and having an inherited susceptibility.

In a study recently conducted in the United Kingdom, researchers found that individuals who had undergone genetic testing felt that information about the gene mutation belonged to the family, while the information about the day-to-day health was their own.[472] The study found that most participants disclosed their test results to their family so that family members could also be tested if they chose. The question of who the test results belong to is important and the answer seems to be both the individual and their family. The empirical evidence suggests that those interviewed think that this is the

[471] Dheensa, Fenwick and Lucassen, 2016, 176.
[472] Dheensa, Fenwick and Lucassen, 2016, 174.

case, but this is also an important and very difficult moral question as well. However, it is not just test results that are needed by those who test positive.

VI.II – Accurate Risk Assessment

An individual's level of risk depends in part on which gene mutations he or she has and how many. This information can be gathered from the test results. However, another part of the risk assessment requires access to a detailed family medical history, particularly the histories of those who have developed cancer.[473] The information required includes knowing precisely what type of cancer they had, the age of onset, and the number of primary tumours at time of diagnosis. The accuracy of the risk assessment depends on the details of the medical history provided. When individuals attempt to provide their family medical history they often lack the in depth knowledge of their relatives' cancer diagnoses that is needed. "Studies have shown that at least 20% of reported cancer diagnoses in relatives are inaccurate."[474] This being the case, access to family medical records can go a long way to producing an accurate risk assessment for the tested individual. However, seeking access to an individual's medical record requires that the relatives in question provide consent. When seeking consent to access medical records the reason for access needs to be disclosed, but disclosing the reason for access requires that the practitioner reveal the tested individual's inherited susceptibility. So, in order to create an accurate risk assessment for the tested individual the practitioner requires consent to disclose the tested individual's

[473] It should be noted that it is possible that not all of the incidence of cancer in a family are related to an inherited susceptibility.
[474] Suthers, 2008, 34.

inherited susceptibility and consent from the relatives to access their medical records.

Seeking consent to access medical records, including test results and possible tissue samples, can be difficult when dealing with living relatives. An individual's medical records are immensely personal and revealing. As noted above, individuals may feel that their genetic test results belong to their family, while their day-to-day health is personal and private. However, it is not just living relatives whose medical histories are needed, but deceased relatives as well. To access a deceased individual's medical history and tissue samples requires going through their estate. This matter can be quite complex. If the deceased individual's estate is handle by someone from within the family the executer must approve any release of information. Given the results from the study discussed above, the executer may feel that providing this information is an invasion of the deceased relative's privacy, or that they would not have wanted to share this information. In some cases the executer of the estate is someone from outside of the family, like a lawyer, and may not have known the deceased very well and would not be able to judge whether the deceased would have been amicable to providing this information. It can also be very difficult for the tested individual to approach a non-related executer about a private health concern, since the executer would likely require some explanation as to why the tested individual is seeking the information in the first place. This can be made more difficult if these types of issues were not outlined by the deceased individual prior to their death.

Creating an accurate risk assessment for the tested individual is important because the risk assessment gives them information that they need to make lifestyle choices. Knowing one's risk gives one the information needed to assess some beliefs that they may have and to make value judgements regarding their life plans or course of actions that can be taken in line with their preferences and goals. In this way, the information provided by an accurate risk assessment may aid the individual in exercising the complex capacities constitutive of autonomy as outlined in chapter three . The tested individual needs access to medical records so that they can make informed decisions about their future. This seems as though it highlights that it can be the case that respecting autonomy of relatives may result in potentially hindering the tested individual's ability to better exercise their autonomy in the future, if any or some number of relatives refuse access to their medical records. Possible conflicts may arise with competing claims to the access of information.

VI.III – Respecting Autonomy and Transformative Experience

In sections IV and V I outlined ways that getting genetic test results can change the tested individual's perspectives, values and perceived options. I explain that receiving either a positive or a negative result from genetic testing can alter how someone sees what options are open to them, how they approach their hobbies, careers, and reproductive choices. The problem here is that the tested individual does not know in advance how receiving either test result will impact on their life and possibly change them. L. A. Paul would describe this type of experience as a 'transformative experience'. It is 'epistemically transformative' in the sense that the individual learns

something from the experience that they could not have learned without the experience, and 'personally transformative' in the sense that it changes who they are by changing their perspective and values.[475] Paul argues that these types of experiences pose a problem for autonomous decision-making because for our decision-making to be rational it must follow "a realistic normative decision theory" to make those decisions.[476] These types of decision theories often require that we imagine how a particular choice will affect us and assign that choice a subjective value based on how we believe that it will satisfy our preferences. They then require that we should choose the act that has the highest expected value.[477] The problem is that a transformative experience changes who we are, including what our preferences might be, and we have no way of knowing in advance how the experience will change us. So, we lack the appropriate evidence required to assign values to the outcomes of the possible actions we can take.[478] If we cannot base our decisions on the subjective values that we assign different outcomes, because we cannot assign different outcomes a subjective value, then arguably we cannot make a rational decision.

An individual must choose to undergo testing and the experience is both epistemically transformative and personally transformative. While, illness might be transformative it is not a transformative experience in the sense that Paul is discussing. An individual cannot elect whether they develop an illness or not, but having cancer is not a prerequisite for genetic testing. Healthy individuals can elect to undergo genetic testing. Genetic testing is not

[475] Paul, 2014, 16-17.
[476] Paul, 2014, 19.
[477] Paul, 2014, 20-21.
[478] Paul, 2014, 22-23.

dissimilar to the example that Paul uses about becoming a parent. When you decide to become a parent you don't know what your child is going to be like, you can't even begin to get information about the child until sometime during gestation. Unless you decide to adopt you pretty much get what you're going to get with little more than your genetic input. Paul's arguments that becoming a parent is a transformative experience are quite convincing and I think that those arguments work for genetic testing. You can decide to undergo genetic testing, but you have no control over the results you get.

Genetic testing for an inherited susceptibility has these same problems. Knowing that one has an inherited susceptibility can change the person in unexpected ways. Going for testing, the individual may feel that knowing will help them to make better lifestyle choices, but will not impact on their life in any other way. If they receive a positive test result it will only give them stronger reasons to maintain a healthy lifestyle through exercise and diet, but that is about it. However, after testing they may develop different preferences regarding reproduction, career, or hobbies. Their preferences have still changed in ways that they had no way of knowing about and the types of preferences that changed may have been preferences that they held as being central to who they were. The changes in preferences, who the individual is, and what it is like for that individual to experience who they are demonstrates that genetic testing could be classed as a transformative experience and run up against the same problems.

Paul's general conclusion is that an individual can make a rational decision to undergo a transformative experience. The individual must ask themselves not whether the outcome would be valuable for them, since this is impossible to

determine; but whether they want to undergo an experience that by its nature will change who they are, their values and perspective. They can make the decision to be changed by the experience, even if they do not know precisely how they will be changed.[479] I think that pre-testing genetic counselling can be essential to both informing the individual that this type of experience is one that can change them and making them aware of the consequences of testing, so that they can decide whether they would like to be changed by this decision even if they are unsure how they will be changed by it. In this way, we can still respect their autonomy.

However, in the afterword of her book, Paul argues that during the informed consent procedure patients are encouraged to imagine possible outcomes and assign subjective values to those outcomes when making a decision. She says that this can give patients a sense of the possible outcomes and that this can help patients to respond positively to the actual outcome.[480] She argues that embedded in this deeply practical method of decision making is the implicit acknowledgment of our "epistemic inability to evaluate transformative experiences."[481]

This later conclusion identifies that it can be helpful for someone to imagine the possible outcomes that they may experience even if they lack the knowledge of how the actual outcomes will change them. Paul argues that this imagining can have a positive impact on how the individual responds to their actual outcome. This can be helpful in this case because the positive impact experienced by the individual may help to reduce the possible

[479] Paul, 2014, 122-123.
[480] Paul, 2014, 140.
[481] Paul, 2014, 140.

negative impact that the knowledge acquired through testing may have on the individual's well-being. While her general conclusion may leave readers feeling as though they have been given little guidance on how to handle transformative experiences, it's a better conclusion than the one that requires that we merely remember that the possible outcomes that we imagine are fictitious. The acknowledgement that this type of decision can change who you are in ways that you cannot predict and the requirement to base your decision on whether you would want it to change you is important. The positive impact that the individual's imagining of possible outcomes may have on their experience of their actual outcome can make the endeavour of imagining possible outcomes beneficial and worthwhile for the individual, even with the acknowledgement that these imaginings are just that. The pre-testing genetic counselling session highlights the areas of one's life that testing can impact. Being made aware of the consequences of testing can help individuals to determine whether they want to undergo testing. It is through the pre-testing genetic counselling that we can truly aim to respect patient autonomy.

Richard Pettigrew argues that the challenges raised by transformative experiences can be mitigated. Pettigrew argues that the conception of decision theory that Paul is addressing is a *deliberative conception of decision theory*, but this is not the only conception of decision theory available; there is also a *preference-first conception of decision theory*. The *preference-first conception* of decision theory acknowledges that the agent has both a utility function and a credence function, but these two functions together represent the ordering of the agents preferences. The preference ordering matches the ordering of

the expected utility relative to the probability of those outcomes. The utilities and credences that the agent has are in virtue of the preferences they have. Where the utility function is the expected value of the outcome for choosing an action, and the credence function is the probability of that particular outcome being the result of the action.[482] On this kind of conception for decision theory an agent can justify choosing an action based on their preferences, but if asked to justify their preferences they will fall short. When asked to justify our preferences we often can provide an answer and we typically use our utilities and credences to do so. Pettigrew argues that we treat our utilities and credences as though they are psychologically real and this is what motivates the *deliberative conception of decision theory*, which Paul focuses on.[483]

It is these deliberative and justificatory practices that are brought out in the *deliberative conception of decision theory* and the practices which Paul highlights as being challenged by transformative experiences. However, Pettigrew argues that the challenges that Paul raises can be side stepped or reformulated so as not to cause problems. With an experience that is epistemically transformative Paul claims that we cannot know about the phenomenological qualities of such an experience and so we do not know what utility value to assign to the action in question.[484] Pettigrew argues that this can be overcome if we reformulate the uncertainty so that it is uncertainty about the world instead of uncertainty about the expected utility, but this approach requires the agent to "have credences over a new set of

[482] Pettigrew, 2015, 766.
[483] Pettigrew, 2015, 767.
[484] Pettigrew, 2015, 767.

dependency hypothesis."[485] Then he asks whether this would pose a new problem. He doesn't think that it does. He argues that utility hypothesis simply specify a numerical unit for utility that the agent would have with each possible outcome and so there is no need to have knowledge of their phenomenal character.[486] Then "once you've set out the various possible utility hypotheses, they are simply empirical hypothesis about which you can accumulate evidence in the usual way."[487] He argues that this can be done by looking at evidence from studies and statistics. However, this need not threaten the authenticity of ones choices in the way that Paul claims. He argues that we frequently use statistical evidence gained from other people to make choices in our lives, like when we decide to exercise because we think it will contribute positively to our health. Why should this be any different with other types of decisions? Pettigrew argues that although the information that is being used does not include information about one's own utility, it is however used as a means to support one's credences "that quantify uncertainty."[488] The evidence used to support these credences take into consideration how similar the sample population is to the agent. If the individual feels that the groups' utilities are in line with their own, then the evidence would support the credence about how likely individual would be to have a similar utility rating. However, if the individual were to find out that the groups' utilities were quite different from their own, then this would provide support for abandoning the credences that they had assigned. So, the individual would still be able to make a decision while being uncertain about

[485] Pettigrew, 2015, 768.
[486] Pettigrew, 2015, 768.
[487] Pettigrew, 2015, 768.
[488] Pettigrew, 2015, 770.

the expected utility because they can seek evidence to support their assignment of credences. For personally transformative experiences Pettigrew argues that an individual make decisions by assuming that their values will change in some specific way and weigh this change against how you value outcomes.[489] However, Pettigrew cautions that the individual should not necessarily put more weight on how they value outcomes now over how they might value outcomes in the future; neither should they put more weight on how they might value outcomes in the further over the present. The weighting system used to make these decisions should privilege neither the present values nor the expected future values that the individual assigns to outcomes.[490] There is still some level of uncertainty of whether the individual will end up valuing outcomes in the way that they imagine they will and it is important not to make all one's decision based on how they think they might change in the future.

Pettigrew's does not argue that Paul has mischaracterised transformative experiences in any way. So, the arguments presented by Pettigrew make no claims about the nature of transformative experiences, but instead about how these experiences might not pose the challenges that Paul claims they do against decision theory. Pettigrew's discussion of how one can avoid the challenges that Paul raises in the case of personally transformative experiences is kind of similar to her conclusion about how we can decide to undergo a transformative experience. Paul's general conclusion is that we should decide whether we want to be changed in some way by an experience, but Pettigrew argues that we can image being changed in some specific way

[489] Pettigrew, 2015, 771.
[490] Pettigrew, 2015, 772.

make decisions based on the expected utilities that of those new values. These two approaches seem consistent, especially if one considers the conclusion Paul provides in the afterwards about informed consent in medicine. Part of the reason that Pettigrew cautions not privileging the utility values the future you would have is because you might not be changed in that way.

Pettigrew's method of addressing epistemically transformative experiences requires that there is data that one can use to assign credences. As far as genetic testing is concerned I'm unsure if there is sufficient evidence available. The method itself does not appear to me to be problematic, but I think that whether it can be applied in a way to mitigate the challenges made by Paul may depend on the type of transformative experience we are considering. The parenthood example would have a lot of evidence complied, both from a statistical standpoint and the kind of anecdotal evidence one might be able to gather for themselves. However, with genetic testing there seems to be considerably less evidence. Where there is evidence that can be used the evidence has be gathered from very specific settings, namely concerning samples who have gotten testing which is likely to include genetic counselling, and there has not yet been much opportunity to conduct longitudinal studies . So, in the case of genetic testing it would seem that the evidence that would be required to assign credences is impoverished and potentially non-reflective of the individual seeking testing. If the individual is seeking genetic testing through the use of a genetic testing kit the evidence available to them may be less reflective of their chosen testing method than opting for a more expensive route. Taking these issues into consideration I

think that Pettigrew's arguments provide good reasons to require genetic counselling alongside genetic testing.

I think that Pettigrew's methods of addressing Paul's challenges hold some merit; they definitely suggest ways of avoiding some of the problems highlighted by Paul. However, I think that Pettigrew's approach may not work for all of the types of experiences that could fall within transformative experiences. Some of these experiences may in time be able to be addressed, or partially addressed, by the methods that Pettigrew proposes.

VII – Considerations in Favour of Offering Genetic Testing

Sections four, five and six mentioned how genetic counselling can help an individual to make an informed choice regarding whether to undergo genetic testing for an inherited susceptibility. Pre-testing genetic counselling is clearly beneficial to the individual seeking testing because they discuss possible consequences that this type of testing can have. This information along with the explanation of the limitations of genetic testing is important for an individual to have prior to testing, and it is crucial for an individual to make an informed decision regarding whether to undergo testing. The pre-testing genetic counselling session may reduce some of the negative impacts that testing may have on an individual. It may also reduce worries about tested individuals developing a nihilist perspective regarding their future. Private genetic testing that does not offer this service and genetic testing kits skip out on this important step for genetic testing. Studies may suggest that people are capable of understanding the results of their genetic test, but there is a difference between understanding the results and understanding the

consequences. Understanding the science does not mean that an individual has considered and understands how this information can impact on their life. Understanding that an inherited susceptibility increases one's risk to developing cancer and our ability to accurately apply that risk to ourselves can be distinct issues. I've highlighted at various points within this thesis that there is a well-established poverty in typical decision-making and our difficulties in applying or assessing our personal risk can hinder our ability to make informed decisions. During the genetic counselling sessions attempts are made to help individuals to come to terms with the possible implications and to mitigate the disparities between understanding the risk and applying it to oneself. I think that there are worries about being adequately informed about genetic testing without the pre-testing genetic counselling session.

Direct-to-consumer genetic testing kits have come onto the market in recent years. Someone can go online and purchase a genetic testing kit at a greatly reduced cost when compared to private genetic testing. The availability of these tests on the market can cause customers to feel as though the tests are reliable and safe, not to mention that they can also feel that spending the money on expensive genetic testing which includes genetic counselling is not necessary. However, approval for the sale of these tests focuses on different aspects of the test than one might think. The regulations on these kinds of tests depend largely on whether the test is deemed a medical or health product or something else. For instance, the full 23 and Me test[491] was approved for sale in the United Kingdom much sooner than it was in the

[491] There are other genetic testing kits that can be purchased online, but the 23 and Me testing kit has gotten a lot of coverage. This is in part because of the publicity of the FDA's reclassification and warning letter that the company had received.

United States. The reasoning behind this earlier approval had to do with the United Kingdom deeming that the test was not a health product, but an information product.[492] The Medicine and Health Products Regulatory Agency (MHRA) deemed that the 23 and Me genetic testing kit was not a health product because it lacked the intention of being a health product. For a product to fall under the jurisdiction of the MHRA the product must be intended for use as a diagnostic tool or for other health purposes.[493] The 23 and Me website states that it is not intended to be used for diagnostic purposes and that if concerned about results, customers should consult their physician.[494] Health Canada has similar views on what is classified as a medical or health product.[495] Therefore, the availability of these kinds of genetic testing kits is not regulated by Health Canada. [496] However, referring to the classification description provided by both of these regulatory agencies the 23 and Me testing kit could very well fall under their regulation. In the United Kingdom the only reason the test is not under their regulation is because the company claims that the test is not intended as a health product.

In the United States the 23 and Me test was originally sold as an ancestry testing kit and thus did not require FDA approval. Once they started

---

[492] "23andMe: Why Have DNA Kits Been Approved in the UK?," *The Week* Accessed on March 1st 2017 http://www.theweek.co.uk/uk-news/61614/23andme-why-have-dna-kits-been-approved-in-the-uk

[493] "Council Directive 93/42/EEC of 14 June 1993 Concerning Medical Devices," Councel of European Communities, Accessed on March 1st 2017 http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CONSLEG:1993L0042:20071011:en:PDF

[494] 23andMe information page, Accessed March 1st 2017 https://www.23andme.com/en-gb/health/

[495] Picard, 2014, online.

[496] Health Canada Guidance on the Risk Based Classification System for Non-In Vitro Diagnostic Devices, Accessed March 1st 2017 https://www.canada.ca/content/dam/hc-sc/migration/hc-sc/dhp-mps/alt_formats/pdf/md-im/applic-demande/guide-ld/gd_rbc_non_ivdd_lg_scr_autres_idiv-eng.pdf

including inherited diseases or conditions as part of their service the FDA stepped in with a warning and prohibited them from providing health related aspects of their test until they demonstrated the accuracy of their tests. 23 and Me was also required to demonstrate that their information regarding the results for any health conditions were accessible to the customers who received them.[497] Once the company had demonstrated that their tests were accurate and that the information concerning the results is accessible their full tests were approved for sale.

It seems problematic that regulatory agencies in places like Canada and the United Kingdom do not consider at home genetic testing kits to be health products, especially when a test clearly seems to fit their classification definitions. These tests claim to inform their customer of their potential future health and their responses to different medication. They clearly claim to provide health information, but they are not regulated in any way by the agencies that are supposed to oversee the use and sale of medical and health products. The approval of the sale of these genetic testing kits as a health product in the United States also fails to acknowledge that these kinds of tests can have a big impact on the tested individual's well-being. The regulatory bodies do not seem to have the well-being of the tested individual in mind, when the only requirements that they have concern accuracy and the provision of information. It is true that the 23 and Me website provides information about genetic counselling, but genetic counselling must be

[497] *FDA News Release,* "FDA Permits Marketing of First Direct-to-Consumer Genetic Carrier Test for Bloom Syndrome," Published online last modified February 19th 2015, Accessed March 1st 2017 https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm435003.htm

sought out by the customer separately as it is not provided through the website.[498] The websites do contain some of the information provided in the pre-screening genetic counselling in their "Family Considerations" tab at the bottom of the page; however, at no point in the ordering process do they require that the customer agree to their terms and condition or acknowledge that they have read that information. There is also no information regarding the risks or limitations of this type of testing—unless this occurs after the individual has purchased the testing kit.[499]

When providing health products and services we should take into consideration how the products or services will impact on the individual's well-being and autonomy. Genetic testing can greatly impact the tested individual's well-being and autonomy. The approval procedure required for offering direct-to-consumer genetic testing kits does not do this, nor does the ordering process include any informed consent procedure. The only informed consent documentation available on the website is concerning the request for the customer's results to be included in the company's genetic research. Genetic counselling can help to reduce or mitigate the possible negative impacts on the tested individual's well-being. Through the provision of information concerning the possible consequences and limitations of testing, the individual is made more aware of how this type of testing can impact on their life and can then make a more informed decision as to whether to undergo testing.

---

[498] Picard, 2014, online.

[499] As my investigation of the website only went so far as the payment process I do not know if further information is provided after the individual has paid for the product. However, providing further information regarding the consequences or risks of testing after the customer has purchased the product would demonstrate some underhanded business tactics.

I think that the inclusion of genetic counselling as a required step in the genetic testing process offered by the healthcare system demonstrates a concern for ensuring that individuals seeking genetic testing understand how the testing may impact them prior to undergoing testing. Private genetic laboratories that offer genetic counselling as part of their process also appear to acknowledge this. The requirement of genetic counselling shows a concern for more than simply the efficiency of the test, but a greater concern for how the test might affect the individual seeking testing. I think that this further consideration is important when determining which types of health products and services to offer to people. Therefore, genetic counselling is an integral part of the genetic testing process. I think that it should be required and that we should not offer any mode of genetic testing that does not include it.

I have argued above that undergoing genetic testing of this kind is a transformative experience, as described by Paul, and as such it can cause challenges for decision-making. Paul's general conclusion is that one must decide whether they would want to be changed in some (unknown) way by the experience. Pettigrew argues that the challenges to decision-making that these kinds of experiences can have can be mitigate through the use of evidence in the decision-making process. Genetic counselling provides the kinds of information that one can use as evidence in their decision-making. However, the scope and quality of the evidence may not be adequate to fully address the kinds of challenges posed by Paul. What is needed is more evidence on the impacts that this type of testing has on the individuals who use it. As it stands right now, genetic counselling can provide the most up-to-date information for individuals seeking testing and help those individuals to

identify the possible impacts that this type of testing can have on their lives. So, the best way to make sure that individuals seeking testing make the most informed choice as possible is to require that they undergo genetic counselling prior to being tested.

It can be argued that the requirement that individuals wishing to undergo genetic testing attend a pre-testing genetic counselling session is paternalistic, particularly when those seeking private testing will be required to incur the extra cost of genetic counselling. However, I think that the genetic counselling requirement is no different from other limitations that we put on individuals when they are making decisions that can have far reaching implications for life and well-being. The requirement for genetic counselling is similar to the requirement to get a house inspection before purchasing a house, or the cooling off period required for contracts. These are limitations that we put on individuals to ensure that they know what they are getting themselves into, prior to the agreements or decisions becoming binding. In the case of genetic testing, the pre-testing genetic counselling session gives the individual information about the possible consequences and limitations of testing prior to the test. Once the individual is given the test results the knowledge is similar to a binding contract, in the sense that they are stuck with it. They cannot change their mind, and unlike a house or a mobile phone contract where they can sell the house or wait for their contract to end, the knowledge that they receive from genetic testing is for life; it cannot be un-known.

VIII - Conclusion

I have outlined some of the potential positive and negative impacts on well-being and autonomy that genetic testing can have. Whether an individual experiences these positive or negative impacts may depend on the personality of the individual. For instance, if the individual is the type of person to see a silver lining in difficult situations they may be more likely to experience more of the positive impacts on their well-being and autonomy or reap the possible benefits more than an individual who typically has a more pessimistic outlook. It could also be the case that even with a personality that sees a silver lining in difficult situations one still experiences a negative impact on their well-being.

The possible impact on well-being and autonomy should be taken into consideration along with the health costs and benefits when determining whether a health or medical product or service should be made available to people. I think that the potential negative impacts that this type of testing can have on an individual's well-being and autonomy should carry more weight than they currently do during deliberations about whether genetic testing should be made available. The positive impacts that this type of testing can have on the tested individual's well-being and autonomy are important: so are the health benefits of early detection, but the possible negative impacts need to be taken into consideration as well. This is particularly important because an inherited susceptibility indicates an increased risk of developing cancer. This means that the individuals whose well-being and autonomy are being affected may never develop the disease, so some of those individuals

will be experiencing potentially negative impacts on their well-being and autonomy without the possible health benefits of early detection.

I have argued that some of the negative impacts to the tested individual's well-being could be reduced or mitigated through genetic counselling. The requirement of genetic counselling aims to reduce the negative impact that this type of testing can have on well-being through the provision of information prior to testing. However, testing without genetic counselling should not be offered. It can be very difficult to know how the knowledge that one has an inherited susceptibility will affect one prior to getting the result and we can't un-know this kind of information once we know it. However, with the pre-testing genetic counselling session we can decide whether we would like to be changed by knowing this information and we can be provided with information that can be used as evidence in our decision-making process. It is true that the information can never be un-known once we have learned it, but knowing and understanding the consequences and limitations of the genetic testing can help us to make a decision about whether we want to face that particular unknown.

Conclusion

This project set out to investigate the tension or apparent tension between the promotion of patient well-being and respect for patient autonomy. The intention was to investigate the relationship between these considerations, and in particular to determine whether one of these aims should be given more weight if they come into conflict, as a general rule applying across different cases. Not surprisingly the answer to this question was no. When two aims or values conflict with one another it makes sense to try to determine whether one is more important than the other. If it turns out that this is not the case, then one can move forward towards investigating what should be done in instances when a conflict or tension arises. This project provides an in depth investigation into the relationship between these two aims and how consideration for both aims weighs up in different situations and contexts. This investigation differs from the sources that are currently available because I have aimed to address both of these aims together and dealt with them each in their own right, and not through the lens of the other aim. Throughout this project I have discussed how a concern for promoting well-being and respecting autonomy apply within the context of cancer care. This was done by looking at two concrete cases; end of life care and genetic testing for an inherited susceptibility.

The investigation into how these concerns apply in these two concrete cases suggests that both of these concerns are important and it is not the case that either always has priority. I conclude that while both are important I do not

think that concern with one of these should take precedence over the other in all situations. This is demonstrated in the conclusion that a 'good death' is one that promotes patient well-being as much as possible and respects patient autonomy for as long as possible. It is also reflected in the conclusion that concerns for the impact on patient well-being and autonomy should be taken into consideration in combination with the health benefits of a test, treatment, or procedure when we are determining whether it should be included for use in medicine. I believe that the importance of both of these values is also highlighted in the recommendation that genetic testing should be offered only in combination with pre- and post-testing genetic counselling. I argued that genetic testing can have a potentially negative impact on the tested individual's well-being and autonomy, but that the inclusion of pre-testing genetic counselling into the testing procedure can help to mitigate this by providing individuals with information regarding the possible consequences of testing. This not only makes people aware of how this kind of testing can impact other aspects of their life, but also helps us to respect their autonomy in what may sometimes be a transformative experience.

It is through the investigation of how concerns for promoting well-being and respecting autonomy apply in these contexts that we can see how there can be a tension between them. However, this investigation also shows how important both are for patient care. I think that by demonstrating how important both promoting well-being and respecting autonomy are to patient care I have shown that one should not be given more weight over the other, as a general rule. I also believe that, by not giving more weight to one of these

values, we help to keep both in check. Neither of these concerns should be given full reign.

Promoting patient well-being can be seen as happening on two levels. The first is taking well-being into consideration when determining what should be offered to people or what tests, treatments, and procedures should be used in medicine, and the second is when we deal with individual patients. This project maintains that the tension between promoting patient well-being and respecting patient autonomy may be real or only apparent. I do not advocate for any particular theory of well-being, and so I am open to the possibility that autonomy is one constituent of well-being. If that were true, any tension that may appear to arise between the two is only an apparent tension. If it is an apparent tension it is apparent in the sense that it is not a tension or conflict between two distinct values, but a tension within well-being. If autonomy is a constituent of well-being than the conflict arises between autonomy and some other constituent, meaning that they both contribute to well-being in some way.

However, I do advocate for a specific type of theory of autonomy. I argued that the correct account of personal autonomy is one that claims that there are a set of complex capacities that are constitutive of autonomy. In this project I used David Richards' account of personal autonomy as an example of what a correct theory of autonomy would look like. We respect patient autonomy through our informed consent procedures. I argued that the moral significance of informed consent does not lie in the consent being a specific type of autonomous action, but that the consent given is an expression of the individual exercising their autonomy. If we look at our informed consent

procedures we include a competency requirement. This requirement attempts to identify features of persons that make it possible for them to give an informed consent. I argued that Tom Beauchamp and Ruth Faden do not give enough weight to our competency requirements when they present their argument that the moral significance of informed consent lies in it being an autonomous action.[500]

I began this investigation by looking at different theories or conceptions of health. Medicine generally focuses on promoting well-being through promoting health. The relationship between health and well-being is complex and broader than one might think at first glance. I argued that health cannot be equated to well-being as the World Health Organisation definition of health does. Nor does the mere absence of disease, illness, and injury encompass the intricacies of our conception of health. I also considered a biological account of health, but this too falls short as it has difficulties in accounting for things like mental health. The social role theory and its considerations of the sick role get at some of our notions about the badness of poor health, but it too is lacking. I also considered a phenomenological theory of health, but deemed that it could not be a standalone theory of health. I proposed that health includes the absence of disease, illness, and injury, but that it also consists of a set of capacities. This proposal implies that health can be measured by degrees. People can be more or less healthy depending on the presence or absence of disease, illness, and injury, but also on their ability to participate in day-to-day life and activities.

[500] More specifically, they argue that, the moral significance of an informed consent is that it is a special kind of autonomous action, it is an autonomous authorisation.

A complete theory of health would need to include definitions of disease, illness and injury. While this did not fit into the scope of this project there does seem to be some consensus about the distinction between disease and illness in the literature. There is surprisingly little written in philosophy about injury.[501] It could be that people think that medicine has done a good job of giving a clear definition of injury. However, it would be really important for a theory of health that includes injury to be able to answer questions such as the following. When does an injury end? If an injury causes permanent damage to an individual, are they forever injured and therefore less healthy, or is there a point where the injury has healed and the lasting effects are classed as something else? Any theory of health which includes an absence of injury would need to answer these questions. The theory that I have put forward is no different. I did, however, include some preliminary remarks about what a complete version of the combination theory might look like. I suggested that the conception of disease would likely be a naturalistic account, while illness would be a phenomenological account. I think that it is important for a theory of health to be phenomenologically informed. I argued that our theory of health influences what we include in medicine, the types of treatments and procedures we offer, and what types of knowledge that is deemed appropriate or applicable to the field. Having a theory of health that is phenomenologically informed can result in a more inclusive approach to

[501] A quick search of the *Stanford Encyclopedia of Philosophy*, *Routledge Encyclopedia of Philosophy*, and philpapers.org shows that there is not much done on injury itself. Injury does appear in conjunction with other topics like law, well-being, and consent, but these do not address questions about the nature of injury. Rather injury is used as an example of harm or a means to further the argument being presented about the actual topic of the paper.

medicine and help to address issues of epistemic injustice experienced by patients.

The relationship between health and well-being is complex, but they are distinct. The reason we are concerned with the promotion of patient well-being is because of the principles of beneficence and nonmaleficence. At the base of these two principles is a concern for well-being. In medicine we typically promote patient well-being through health because medical professionals have the knowledge and skills to aid people in these ways. However, the relationship between health and well-being is complex and intimately intertwined no matter which type of theory of well-being one subscribes to. However, the fact that medicine and medical science focus on health as its area of specialisation does not mean that it should look at health in isolation. Because of the far reaching impact that an individual's health can have on their well-being, we should take well-being into consideration when determining which test, treatments, and procedures should be offered in medicine, not just which test, treatment, or procedures we should offer to any particular patients. In this sense our concern for promoting well-being comes prior to any particular patient being involved.

I argued in chapter five that when thinking about whether a test, treatment, or procedure should be offered, we should also take into consideration how the test, treatment, or procedure will impact on people's well-being and autonomy more generally and not just focus on the possible health benefits and costs associated with the proposed test, treatment, or procedure. This conclusion extends from the arguments presented about genetic testing for an inherited susceptibility to cancer. I argued that the impact that genetic testing

can have on the tested individual's well-being and autonomy should be given more weight than it currently is when determining whether we should be offering this type of testing to people. I did not argue that this type of testing should not be offered, but instead that we should take steps to try to reduce the impact that this kind of testing can have on the individual's well-being and autonomy by ensuring that the individual is aware of the possible consequences that it can have for them. We can do this through providing both pre- and post-testing genetic counselling for those seeking genetic testing. While the arguments presented pertain to genetic testing, I do not believe that genetic testing is entirely unique in this respect and I think these arguments can be extended to other tests, treatments, and procedures.

Considering how a test, treatment, or procedure may impact on the individual's well-being acknowledges the complex and interconnected relationship between health and well-being, noting that health cannot be addressed in isolation from the impact that it has on other areas of an individual's life. When considering how a test, treatment, or procedure may affect an individual's well-being we can also look for ways to reduce the possible negative effects on well-being, so that people can still have the positive health benefits it will provide. Genetic testing for an inherited susceptibility to cancer can have many positive effects for the tested individual. Providing genetic counselling to individuals seeking testing can help them to understand the possible consequences and determine whether testing is right for them, while still having access to testing and the benefits that it can provide. This is an example of how we can take the impact that a test can have on well-being into consideration when determining whether to

offer it and find a way to try to reduce the possible negative effects of the test while still utilizing the test.

Health can have a big impact on an individual's well-being, but there are other aspects of well-being that also need to be considered. Proposed tests, treatments, and procedures may promise health benefits if offered, but a concern for other aspects of well-being should also be taken into consideration when determining whether to offer them. This does not mean that *any* negative impact on well-being should outweigh the health benefits, but that we should evaluate possible negative impacts on well-being in combination with the possible health benefits. Steps should be taken to mitigate or eliminate the negative impact the proposed test, treatment, or procedure will have on patient well-being. Attempts to mitigate the negative impact on well-being can be as simple as ensuring that the individual is informed of the impact that the proposed test, treatment, or procedure can have on their well-being in order to aid them in making an appropriately informed decision. The considerations here are similar to those requiring the provision of pre-testing genetic counselling. Genetic counselling not only helps people to understand the possible consequences and limitations of testing, but it also helps them to exercise their autonomy when facing a possibly transformative experience. We are taking steps to ensure that the individual is making as well informed a decision as possible, and giving them the opportunity to decide whether they would like their values and experience of who they are to be changed by this test, even if they cannot know how the test might change them. Taking into account considerations

concerning patient well-being and autonomy will allow us to provide better care for patients.

There are other times in treatment when we may be required to look not only at the health of the individual, but also at their well-being more generally—for instance, during end of life care. Once an individual has reached a terminal stage in their cancer, attempts to improve health give way to a more general concern for patient well-being. During terminal illness the dying process is extended over some duration of time. This time may be days or months, and the person's death may go more or less well for them. I argued that a 'good death' is one that promotes well-being as much as possible and respects autonomy for as long as possible. There is a standard view of a 'good death' presented in the literature that influences practice. The standard view is composed of a list of criteria which include: awareness, both in the sense of being cognitively present and being aware that one is dying; being surrounded by family and loved ones; taking part in planning end of life care; and being as free as possible from physical, psychological, and emotional pain, suffering, and distress.

I have found evidence in the literature that this list of criteria is viewed as being required for a death to be a 'good death'. If these criteria are required for a 'good death', then I think that the standard view is problematic for several reasons. The standard view limits the individuals who can have a good death to those individuals who can be clearly identified as having entered into the dying process, namely the terminally ill. The standard view is also counterintuitive; some people believe that a 'good death' is one that occurs in old age and in one's sleep. If an individual remains relatively

healthy into their old age and dies peacefully in their sleep, then they have only managed to fulfil one of the criteria on the standard view; the criterion relating to pain, suffering, and distress. The standard view does not take into account the differences between people and how achieving these criteria may negatively impact on their well-being. If achieving the criteria reduces the individual's well-being it seems hard to see how it makes the person's death go well for them. However, my arguments against the standard view only hold if the standard view is seen as a list of criteria required for a 'good death', as a kind of check list to be used for everyone. If the standard view is a list of recommendations or suggestions that often help one to have a 'good death', but that are not required, then I think that this list has merit.

If the standard view is a list of recommendations or suggestions for promoting a 'good death', then we still need a theory of what makes a death a 'good death', or what makes an individual's death go well for them. This is where my theory for a 'good death' can be useful. A 'good death' is one that promotes well-being as much as possible and respects autonomy for as long as possible. This view is completely compatible with the standard view, if the standard view is a list of suggestions that might help an individual's death to go well for them. My view also allows that each individual's death may go better for them for different reasons. What would make a death go well for one person may be different from what will make a death go well for another. It may be the case that for many people being with family and loved ones will make their death go well for them, but for others it may not. Promoting the well-being of the dying individual allows us the flexibility that a view with a list of required criteria does not. My theory claims that we should respect

autonomy for as long as possible. This is an important feature because sometimes as we age or near death we begin to lose the capacities constitutive of autonomy, and we may no longer be capable of exercising our autonomy. By including 'as long as possible' in the theory of a 'good death' we show recognition of the possible loss of the ability to exercise one's autonomy.

However, I think that respecting the patient's autonomy becomes particularly important in their end of life care. It is important that the individual have as much control over their dying process as possible, because it is the end of their life and they should be able to exit it in a way that fits with their values. It may be the case that their choices about how they want to exit their life reduce their well-being in some ways. For example, an individual may wish to be cognitively present for as long as possible and so refuse or minimize the use of pain medication. Being in pain is likely to reduce the individual's well-being, but their decision to choose some preferences or values over experiencing less pain can be very important to the individual and their decision should be respected. There is the possibility that the individual underestimated the amount of pain that they would experience and their ability to exercise their autonomy may be greatly reduced due to the pain. In this instance, it may be hard to determine whether we should respect their earlier decision or a possibly less autonomous decision later when they are actually experiencing the pain. The answer to this may depend on to what extent they refused or minimized the offer of pain medication, or if they made the purpose of their decision clear. If they expressed the view that they wanted minimal amounts of pain medication so they can spend time with family, or to be more cognitively present, then if they were delirious with

pain the purpose of their refusal is not being met and we may be permitted to marginally increase the pain medication to support the intended purpose of their request. On the other hand, if they refused pain medication completely we may have a conundrum as the individual is no longer autonomous, so they cannot change their mind autonomously, but giving them the pain medication would go against their explicit wishes or their autonomous refusal. This is one of those difficult situations for which we may not be able to have a standard answer. It may be that at this time we should turn to a third party for guidance, preferably one that knows the patient well and may be better equipped to make a decision that will fit best with the patient's values. I have provided a discussion of Sumner's arguments for the moral permissibility of assisted dying. Another advantage to the conception of what makes a death go well of the dying individual is that it is also compatible with assisted dying.

These two examples have illustrated that the relationship between promoting patient well-being and respecting patient autonomy is complex. Both of these concerns play an important role in how medical professionals interact with patients through different situations in the context of cancer care. Attempts to promote well-being and respect autonomy often point in the same direction, but sometimes these two aims can come into real or apparent conflict. When they do conflict we should sometimes choose to fulfil one aim and sometimes the other. However, the judgements concerning which of these aims to favour in a given situation depends on understanding both the medical and ethical aspects of the situation. This complex relationship and the judgement to

favour one aim over the other cannot be captured in an overarching priority rule.

There are many aspects of cancer care that have not been addressed in this project—such as treatment, screening, research, and children's oncology, to name a few. I chose genetic testing for an inherited susceptibility to cancer and end of life care as the example cases because I thought that they would be interesting and the tension between well-being and autonomy may not be as readily apparent as in some other areas of cancer care. I think that we can do things in hopes of reducing the tension or apparent tension between promotion of patient well-being and respect for patient autonomy, like including considerations about how tests, treatments, or procedures may impact well-being and autonomy in our deliberations about what should be offered in medicine. While the doctor-patient interactions may be more typically focused on the health and health outcomes of the patient, we can still address a more general concern for well-being and autonomy through policy and the types of test, treatments, procedures, and services that are offered.

This project proposes a theory of health and an alternative conception of a good death. Both of these theories boast a better fit with our ordinary notions associated with health and what makes a person's death go well for them. I provided an in-depth analysis of how our considerations for promoting patient well-being and respecting patient autonomy weigh up when looking at genetic testing for an inherited susceptibility to cancer and end of life care. This analysis has concluded that there is no overarching rule for which of these aims should have priority across situations, but this investigation can be

used to understand the intricate relationship between the two. I have argued that attempts to mitigate the negative impact that a test, treatment, or procedure may have on well-being and autonomy could result in providing more information to the patient, making them aware of the possible consequences can help them to side step some of the possible negative impacts on their well-being. In turn, this would also help the individual to make a more informed decision regarding the proposed test, treatment, or procedure, so it would result in aiding them to better exercise their autonomy. Paul argues that imagining the possible outcomes of a procedure can help the individual to respond more positively to the actual outcome, even if it is different from the outcome that they imagined.[502] This being the case it is plausible to argue that in some senses aiming to promote well-being or to provide more information to aid in the individual's ability to exercise their autonomy can help to further the other aim, whether that is promoting well-being or respecting autonomy. While these two aims can come into tension or appear to come into tension, they can also each help to contribute to achieving the other aim at times. The investigations in this project have shown that further analysis in other areas of cancer care is needed to see how the relationship between these two aims differs in those other contexts.

[502] Paul, 2014, 139-140.

Bibliography

Printed Sources

Andalo, Debbie (2015) "Superdrug is the First Retailer in the World to Sell DNA Testing Kits in Store," *The Pharmaceutical Journal,* Vol. 294 Accessed on March 1st 2017 http://www.pharmaceutical-journal.com/news-and-analysis/superdrug-is-first-retailer-in-the-world-to-sell-dna-testing-kit-in-store/20068268.article .

Arneson, Richard (1999) "Human Flourishing Versus Desire Satisfaction," *Social Philosophy and Policy,* Vol.16 pp.113-142.

Beauchamp, Tom L. and James F. Childress (1994) *Principles of Biomedical Ethics* 4th ed. Oxford University Press: Oxford.

Berlinger, N. and Flamm, A.L. (2009) "Define 'Effective': The curious Case of Chronic Cancer," *The Hastings Center Report*, Vol.39 pp. 17-20.

Bertenthal, Bennett I. and Kurt W, Fischer (1978) "Development of Self-Recognition in the Infant," *Developmental Psychology,* Vol. 14, pp. 44-50.

Bickenbach, Jerome (2017) "WHO's Definition of Health: Philosophical Analysis", *Handbook of the Philosophy of Medicine*, Thomas Schramme and Steven Edwards (eds.) Springer Nature: Dordrecht.

Boorse, Christopher (1975) "On the Distinction Between Disease and Illness," *Philosophy & Public Affairs,* Vol. 5, pp. 49-68

-(1977) "Health as a Theoretical Concept," *Philosophy of Science*, Vol.44, pp. 542-573.

Bresnahan, Mary Jiang, Kami Silk, and Jie Zhuang (2013) "You Did This to Yourself! Stigma and Blame in Lung Cancer," *Journal of Applied Psychology,* Vol. 43, pp. E132-E140.

Buchman, Daniel Z., Anita Ho, and Daniel S. Goldberg (2017) "Investigating Trust, Expertise, and Epistemic Injustice," *Biomedical Inquiry*, Vol.14, pp. 31-42

Carel, Havi (2008) *Illness*, Acumen Publishing Limited: Durham.

- (2013) "Ill, but Well: A Phenomenology of Well-Being in Chronic Illness," *Disability and the Good Human Life*, Jerome E. Bickenbach, Franziska Felder and Barbara Schmits (eds.), Cambrige University Press: Cambridge.

Carel, Havi and Ian James Kidd (2017) "Epistemic Injustice in Medicine and Healthcare, *The Routledge Handbook of Epistemic Injustice*, Ian James Kidd, Jose Medina, Gaile Pohlhaus, Jr. (eds.), Routledge.

Carey, Nessa (2015) *Junk DNA: A Journey Through the Dark Matter of the Genome*, Icon Books Ltd.: London.

Charmaz, Kathy and Dna Rosenfeld (2009) "Chronic Illness," *The New Blackwell Companion to Medical Sociology,* W.C. Cokerham (ed.), Wiley-Blackwell: Oxford, pp. 312-333.

Choi, Jenny, Steven R. Fauce and Rita B. Effos (2008) "Reduced Telomerase Activity in Human T Lymphocytes Exposed to Cortisol," *Brain, Behavior, and Immunity,* Vol. 22, Published online, Accessed June 21st 2017 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2386249/.

Colburn, Ben (2010) *Autonomy and Liberalism,* Routledge: London.

Cooper, Rachel (2002) "Disease", *Studies in History and Philosophy of Biological and Biomedical Sciences,* Vol. 33, pp. 263-282.

Crites, Joshua and Eric Kodish (2012) "Unrealistic Optimism and the Ethics of Phase I Cancer Research" *Journal if Medical Ethics*, Vol. 39, pp. 403-406

D'agincourt-Canning, Lori (2010) "Bodies, Connectedness, and Knowledge: a Contextual Approach to Hereditary Cancer Genetics," *Feminist Bioethics*, Jackie Leach Scully, Luarel Baldwin-Ragaven and Petya Fitzpatrick (eds.), Johns Hopkins University Press: Baltimore, pp. 139-156.

Dekeuwer, Catherine and Simone Bateman (2011) "Much More Than a Gene: Hereditary Breast and Ovarian Cancer, Reproductive Choices and Family Life," *Medicine, Health Care and Philosophy,* Vol. 16 pp. 231-244.

Dheensa, sandi, Angela Fenwick, and Anneke Lucassen (2016) "'Is This Knowledge Mine and Nobody Elses's? I Don't Feel That Way.' Patient Views About Consent, Confidentiality and Information-sharing in Genetic Medicine," *Journal of Medical Ethics,* Vol. 42, pp. 174-179.

Dworkin, Gerald (1981) "The Concept of Autonomy," *Science and Ethics,* Rudolf Haller (ed.), Rodopi: Amsterdam, pp. 203-213.

- (1988) *The Theory and Practice of Autonomy*, Cambridge University Press: Cambridge.

Faden, Ruth R. and Tom L. Beauchamp (1986) *A Theory and History of Informed Consent,* Oxford University Press: Oxford.

Fricker, Miranda (2006) "Powerlessness and Social Interpretation," *Episteme*, Vol. 3, pp. 96-108

- (2007) *Epistemic Injustice: Power & the Ethics of Knowing*, Oxford University Press: Oxford.

Fletcher, Guy (2013) "A Fresh Start for the Objective-List Theory of Well-Being," *Utilitas,* Vol.25 pp.206-220.

Francke, U., C. Dijamco, A.K. Kiefer, N. Erikson, B. Moiseff, J.Y. Tung, and J.L. Mountain, (2013) "Dealing with the Unexpected: Consumer Responses to Direct-Access BRCA Mutation Testing," *Peer J,* Accessed on March 5th 2017 https://peerj.com/articles/8/.

Frankfurt, Harry G. (1971) "Freedom of Will and the Concept of a Person," *The Journal of Philosophy,* Vol. 68, pp. 5-20.

Gabriel, Janice (2004) "What is Cancer?", *The Biology of Cancer*, Janice Gabriel (ed.) Whurr Publishers: London.

Gadamer, Hans-Georg (1996) *The Enigma of Health,* Stanford University Press: Stanford.

Gilmore, Cody (2013) "When Do Things Die?," *The Oxford Handbook of Philosophy of Death,* Ben Bradley, Fred Feldman, and Jens Johansson (eds.), Oxford University Press: Oxford

Hausman, Daniel M. (2015) *Valuing Health: Well-being Freedom, and Suffering*, Oxford University Press: Oxford.

Haybron, Daniel M. (2008) *The Pursuit of Unhappiness: The Elusive Psychology of Well-Being,* Oxford University Press: Oxford.

Haynes, Graeme A. and James M. Olson (2006) "Coping with Threats to Just World Beliefs: Derogate, Blame, or Help?," *Journal of Applied Social Psychology,* Vol. 36, pp. 664-682.

Heathwood, Chris (2010) "Welfare," In John Skorupski (ed.) *The Routledge Companion to Ethics*, Routledge: London.

Hodgson, Shirley and Gareth Evans (1998) "The Inherited Basis of Cancer," *Inherited Susceptibility to Cancer: Clinical, Predictive and Ethical Perspective,"* William D. Foulkes and Shirley V. Hodgson (eds.), Cambridge University Press: Cambridge.

Huang, Caroline J. and Matthew L. Baum (2011) "A Rational Basis for Chemoprevention of Prostate Cancer," *The American Journal of Bioethics,* Vol. 11 pp. 27-29.

Justman, Stewart (2011a) "Forfeited Health: Response to Open Peer Commentaries on 'What's Wrong with Chemoprevention of Prostate Cancer?'," *The American Journal of Bioethics,* Vol. 11 pp. W1-2.

- (2011b) "What's Wrong With Chemoprevention of Prostate Cancer?," *The American Journal of Bioethics,* Vol.11 pp. 21-25.

Kagan, Shelly (1998) *Normative Ethics*, Westview Press: Boulder.

- (2009) "Well-Being as Enjoying the Good," *Philosophical Perspectives,* Vol.23 pp.253-272.

Kim, Shinmi and Yunjung Lee (2003) "Korean Nurses' Attitudes to Good and Bad Death, Life-Staining Treatment and Advance Directives," *Nursing Ethics,* Vol. 10, pp. 624-637.

Kingma, Elselijin (2017) "Disease as Scientific and as Value-Laden Concept", *Handbook of the Philosophy of Medicine*, Thomas Schramme and Steven Edwards (eds.) Springer Nature: Dordrecht.

Lauinger, William (2013) "The Missing-Desire Objection to Hybrid Theories of Well-Being," *Southern Journal of Philosophy,* Vol.51 pp.270-295.

Law, Iain and Heather Widdows (2007) "Conceptualising Health: Insights from the Capability Approach" *Health Care Analysis*, Vol. 16 pp. 303-314.

Mak, June Mui Hing and Michael Clinton (1999) "Promoting a Good Death: an Agenda for Outcomes Research – a Review of Literature," *Nursing Ethics*, Vol. 6, pp. 97-106.

Martin, Carol Lynn, and Diane Ruble (2004) "Children's Search for Gender Cues: Cognitive Perspectives on Gender Development," *Current Directions in Psychological Science,* Vol. 13 pp. 67-70.

Mill, John Stuart (2001) *Utilitarianism and the 1868 Speech on Capital Punishment*, second edition, Edited with an introduction by George Sher, Hackett Publishing Company, Inc.: Cambridge.

Miller, Franklin G. (1995) "The Good Death, Virtue, and Physician-Assisted Death: an Examination of the Hospice Way of Death," *Cambridge Quarterly of Healthcare Ethics,* Vol. 4, pp. 92-97.

Mino, Jean-Christopher and France Lert (2005) "Beyond the Biomedical Model: Palliative Care and Its Holistic Model," *HEC Forum,* Vol. 17, pp. 227-236.

Nussbaum, M.C. (1992) "Human Functioning and Social Justice: In Defence of Aristotelian Essentialism," *Political Theory,* Vol. 20 pp. 216-222.

Olthuis, Gert and Wim Dekkers (2005) "Quality of Life Considered as Well-Being: Views from Philosophy and Palliative Care," *Theoretical Medicine and Bioethics,* Vol. 26, pp. 307-337.

Parfit, Derek (2011) *On What Matters Volume 1,* Oxford University Press: Oxford.

- 2013 "What Makes Someone's Life Go Best", in *Ethical Theory: an Anthology 2nd Edition,* Russ Shafer-Landau (ed.), Wiley-Blackwell: Oxford

Parker, Lisa S. (1995) "Breast Cancer Genetic Screening and Critical Bioethics' Gaze," *The Journal of Medicine and Philosophy*, Vol. 20 pp. 313-337.

Paul, L.A. (2014) *Transformative Experience,* Oxford University Press: Oxford.

Pettigrew, Richard (2015) "Transformative Experience and Decision Theory", *Philosophy and Phenomenological Research*, Vol. 91, pp. 766-774.

Philips, Jean M. and Stanley M. Gully (2013) *Organizational Behavior: Tools for Success* 2nd Edition, South Western Educational Publishing: Mason, OH.

Piot-Ziegler, C., M.L. Sassi, W. Raffoul, and F. Delaloye (2010) "Mastectomy, Body Deconstruction, and Impact on Identity: a Qualitative Study," *British Journal of Health Psychology,* Vol. 15, pp. 479-510.

Plutynski, Anya (2012), "Ethical Issue in Cancer Screening and Prevention," *Journal of Medicine and Philosophy,* vol. 37 pp.310-323.

Press, Nacy, Jennifer R. Fishman and Barbra A. Koening (2000) "Collective Fear, Individualized Risk: Social and Cultural Context of Genetic Testing for Breast Cancer," *Nursing Ethics,* Vol. 7, pp. 237-249.

Prusak, Bernard G. (2013) *Parental Obligations and Bioethics: The Duties of a Creator,* Routledge: Abingdon.

Randall, Fiona and R.S. Downie (1996) *Palliative Care Ethics: A Good Companion*, Oxford Medical Publications: Oxford.

Randy, Mohamed Y. and Joseph L. Verheijde (2012) "Distress from Voluntary Refusal of Food and Fluids to Hasten Death: What is the Role of Continuous Deep Sedation?," *Journal of Medical Ethics,* Vol. 28, pp. 510-512.

Richards, David A. J. (1981) "Rights and Autonomy," *Ethics,* Vol. 92, pp. 3-20.

Richman, K.A. (2004) *Ethics and the Metaphysics of Medicine: Reflections on Health and Beneficence*, The MIT Press: London.

Scanlon, T.M. (1986) "The Significance of Choice," *The Tanner Lectures on Human Values,* Delivered at Brasenose College, Oxford University.

Scarre, Geoffery (2012) "Can There be a Good Death," *Journal of Evaluation in Critical Practice*, Vol. 18, pp. 1082-1086.

Schenck, David P. and Lori A. Roscoe (2009) "In Search of a Good Death," *Journal of Medical Humanities,* Vol. 30, pp. 61-72.

Seedhouse, David (2001) *Health: the foundations for achievement*, 2nd ed., John Wiley & Sons: Chichester.

- (2002) *Total Health Promotion: Mental Health, Rational Fields and the Quest for Autonomy*, John Wiley & Sons: Chichester.

Smythe, Thomas W. and Thomas G. Evans (2007) "Intuition as a Basic Source of Moral Knowledge," *Philosophia*, Vol. 35, pp. 233-247.

Stuckler, David and Sanjay Basu (2013) *The Body Economic: Why Austerity Kills*, The Penguin Group: London.

Sumner, L.W. (2011) *Assisted Death: A Study in Ethics and Law*, Oxford University Press: Oxford

Suthers, Graeme (2008) "Privacy and Property Issues for Familial Cancer Service," *Bioethical Inquiry,* Vol. 5 pp. 33-37.

Svenaeuse, Fredrik (2013) "Naturalistic and Phenomenological Theories of Health: Distinctions and Connections," *Royal Institute of Philosophy Supplement*, Vol. 72, pp. 221-238.

Tabery, James (2009) "From a Genetic Predisposition to an *Interactive Predisposition*: Rethinking the Ethical Implications of Screening for Gene-Environment Interactions," *Journal of Medicine and Philosophy,* Vol. 34, pp. 27-48.

Thomasma, David (1997) "Ensuring a Good Death," *Bioethics Forum,* Vol. 13, pp. 7-17.

Woods, Simon (2005) "Scientific Contribution: Respect for Persons, Autonomy and Palliative Care," *Medicine, Health Care and Philosophy,* Vol. 8, pp. 243-253.

Zahedi, Farzaneh and Bagher Larijani (2007) "Cancer Ethics from the Islamic Point of View," *Iran J Allergy Asthma Immunol,* Vol.6 pp. 17-24

Websites and Encyclopaedia Entries

23 and Me website, https://www.23andme.com/en-gb/health/ Accessed March 4th, 2017

Arbor, Ann, (2015) "Consumers of Commercial Genetic Tests Understand More Than Many Believe," *Michigan News*: University of Michigan, Published online June 22nd 2015, Accessed March 5th 2017 http://ns.umich.edu/new/releases/22972-consumers-of-commercial-genetic-tests-understand-more-than-many-believe .

Beauchamp, Tom, "The Principle of Beneficence in Applied Ethics," *The Stanford Encyclopedia of Philosophy* (Winter 2013 Edition), Edward N. Zalta (ed.), Accessed on November 5 2014 http://plato.stanford.edu/archives/win2013/entries/principle-beneficence.

Christman, John, "Autonomy in Moral and Political Philosophy," *The Stanford Encyclopedia of Philosophy* (Spring 2015 Edition), Edward N. Zalta (ed.), Accessed on August 28th 2017 https://plato.stanford.edu/cgi-bin/encyclopedia/archinfo.cgi?entry=autonomy-moral .

"Council Directive 93/42/EEC of 14 June 1993 Concerning Medical Devices," Council of European Communities, Accessed on March 1st 2017 http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CONSLEG:1993L0042:20071011:en:PDF.

"Direct-to-Consumer Genetic Testing Kits," *Harvard Health Publications: Harvard Women's Health Watch*, Harvard Medical School: Published online September 2010, Accessed on February 23rd 2017 http://www.health.harvard.edu/newsletter_article/direct-to-consumer-genetic-testing-kits.

Dying Matters, Accessed November 15th 2015 http://dyingmatters.org/page/frequently-asked-questions.

Eyal, Nir "Informed Consent," *The Stanford Encyclopedia of Philosophy* (Fall 2012 Edition), Edward N. Zalta (ed.), December 8th 2014 http://plato.stanford.edu/archives/fall2012/entries/informed-consent/.

FDA News Release, "FDA Permits Marketing of First Direct-to-Consumer Genetic Carrier Test for Bloom Syndrome" Published online, last modified February 19th 2015, Accessed March 1st 2017 https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm435003.htm .

Formaldehyde Fact Sheet, Accessed March 4th 2017 https://www.cancer.gov/about-cancer/causes-prevention/risk/substances/formaldehyde/formaldehyde-fact-sheet.

Genetic Disorders UK, Accessed December 20th 2018 https://www.geneticdisordersuk.org/aboutgeneticdisorders/genetictesting

Hankinson, R.J. (1998). Hippocratic medicine. In E. Craig (Ed.), *Routledge Encyclopaedia of Philosophy*. London: Routledge. Accessed on February 20th 2014 http://www.rep.routledge.com/article/A060SECT2.

Health Canada Guidance on the Risk Based Classification System for Non-In Vitro Diagnostic Devices, Accessed March 1st 2017 https://www.canada.ca/content/dam/hc-sc/migration/hc-sc/dhp-mps/alt_formats/pdf/md-im/applic-demande/guide-ld/gd_rbc_non_ivdd_lg_scr_autres_idiv-eng.pdf.

"Hearing Loss at Birth (Congenital Hearing Loss)," American Speech-Learning-Hearing Association Accessed July 18th 2017 http://www.asha.org/public/hearing/Congenital-Hearing-Loss/.

Ismael, Jenann (unpublished) "Death" https://philpapers.org/rec/ISMD Accessed on 23/09/2015

"Implicit Bias," Kirwan Institute for the Study of Race and Ethnicity, The Ohio State University Accessed November 1st 2015 http://kirwaninstitute.osu.edu/research/understanding-implicit-bias/

Luper, Steven (2016) "Death," *The Stanford Encyclopedia of Philosophy,* (Summer 2016 edition), Edward N. Zalta (ed.) Accessed on July 25th 2017 https://plato.stanford.edu/archives/sum2016/entries/death/

MacGill, Markus (2017) "What Should My Heart Rate Be?", *Medical News Today,* Accessed November 27th 2018 https://www.medicalnewstoday.com/articles/235710.php

Meikle, James (2015) "Superdrug Criticised by Doctors for Stocking Genetic Self-Testing Kits", *The Guardian*, Accessed December 31st 2018 https://www.theguardian.com/science/2015/mar/31/superdrug-criticised-doctors-genetic-self-testing-kits

Murphy, Dominic, "Concepts of Disease and Health," *The Stanford Encyclopedia of Philosophy* (Summer 2009 Edition), Edward N. Zalta (ed.), Accessed on February 20th 2014 http://plato.stanford.edu/archives/sum2009/entries/health-disease/.

-"Concepts of Disease and Health", *The Stanford Encyclodedia of Philosophy* (Spring 2015 Edition), Edward N. Zalta (ed.) Accessed February 25th 2018 https://plato.stanford.edu/archives/spr2015/entries/health-disease/

NHS Genetic Testing and Counselling, Accessed March 1st 2017 http://www.nhs.uk/Conditions/Genetics/Pages/genetic-testing-and-counselling.aspx.

NHS Predictive Genetic Tests for Cancer, Accessed March 1st 2017 http://www.nhs.uk/Conditions/predictive-genetic-tests-cancer/Pages/Introduction.aspx.

NHS Seasonal Affective Disorder, Accessed on April 16th 2014 http://www.nhs.uk/conditions/seasonal-affective-disorder/Pages/Introduction.aspx.

NHS Sickle Cell Anaemia, Accessed on April 15th 2014 http://www.nhs.uk/conditions/Sickle-cell-anaemia/Pages/Introduction.aspx.

NHS Whooping Cough, Accessed on March 3rd 2014 http://www.nhs.uk/Conditions/Whooping-haycough/Pages/Introduction.aspx.

Oxford English Dictionary, s.v. "eidetic," Accessed July 13th 2017, https://en.oxforddictionaries.com/definition/eidetic.

Picard, Andre (2014) "Controversial Genetic Self-Testing Kits Coming to Canada," *The Globe and Mail,* Published online October 2nd 2014, Accessed on March 1st 2017 https://www.theglobeandmail.com/life/health-and-fitness/health/genetic-self-testing-kits-to-come-to-canada/article20885678/.

Prieto, Luis and Jose (2003) "Problems and Solutions in Calculating Quality-Adjusted Life Years (QALYs)", *Health Qual Life Outcomes*, Vol. 1 no.80 Published on like December 19th 2003 Accessed on November 27th 2018 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC317370/

Roberts, M.A. (2015) "The Nonidentity Problem," *Stanford Encyclopedia of Philosophy* (Winter 2015 Edition), Edward N. Zalta (ed.) Accessed on March 1st 2017 https://plato.stanford.edu/entries/nonidentity-problem/.

Roland, Jay (2018) "Is a Low Heart Rate Dangerous?", *University Health News Daily,* Accessed November 27th 2018 https://universityhealthnews.com/daily/heart-health/low-heart-rate-dangerous/

Sherman, Mark (2014) "Why We Don't Give Each Other a Break: Annoy? Peeved? The Fundamental Attribution Explains it all," *Psychology Today*, Published online June 20th 2014, Accessed on March 5th 2017 https://www.psychologytoday.com/blog/real-men-dont-write-blogs/201406/why-we-dont-give-each-other-break.

Simmons, A. John (1998) "Consent," *Routledge Encyclopedia of Philosophy,* Accessed October 19th 2015 https://www.rep.routledge.com/articles/consent/v-1/meaning-and-importance.

Stoljar, Natalie (2014) "Feminist Perspectives on Autonomy," *The Stanford Encyclopedia of Philosophy* (Spring 2014 Edition), Edward N. Zalta (ed.) Accessed on December 8th 2014 http://plato.stanford.edu/archives/spr2014/entries/feminism-autonomy.

- (2018) "Feminist Perspectives on Autonomy," *The Stanford Encyclopedia of Philosophy* (Wither 2018 Edition), Edward N Zalta (ed.) Accessed December 22nd 2018 https://plato.stanford.edu/archives/win2018/entries/feminism-autonomy/

The Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care Research Group Seminar, "The Hospice Movement – Then and Now: From Cicely Saunders' Brother" Accessed December 31st 2018

https://www.nottingham.ac.uk/research/groups/ncare/events/seminar-24-sept-2015.aspx

The Week, "23andMe: Why Have DNA Kits Been Approved in the UK?," Published online December 2nd 2014, Accessed March 1st 2017 http://www.theweek.co.uk/uk-news/61614/23andme-why-have-dna-kits-been-approved-in-the-uk .

Williams, Garrath (2014) "Kant's Account of Reason," *The Stanford Encyclopedia of Philosophy* (Spring 2014 Edition), Edward N. Zalta (ed.) Accessed September 20th 2015 http://plato.stanford.edu/archives/spr2014/entries/kant-reason/.

World Health Organisation "Ambient air pollution: Health impacts" Accessed November 22nd 2018 https://www.who.int/airpollution/ambient/health-impacts/en/

World Health Organisation s.v. "Health" Accessed on February 16th 2014 http://www.who.int/about/definition/en/print.html.

World Health Organisation s.v. "Palliative Care" Accessed on December 6th 2015 http://www.who.int/cancer/palliative/definition/en/.

World Health Organisation "Social Determinants of Health: Evidence" Accessed on November 14th 2018 https://www.who.int/social_determinants/themes/en/