

**INFORMED CONSENT AND JUSTIFIED HARD  
PATERNALISM**

**by**

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A thesis submitted to the  
University of Birmingham  
for the degree of  
DOCTOR OF PHILOSOPHY

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April 2012

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## **ABSTRACT**

According to the doctrine of informed consent medical procedures are morally permissible when a patient has consented to the treatment. Problematically it is possible for a patient to consent to or refuse treatment which consequently leads to a decline in her best interests. Standardly, such conflicts are resolved by prioritising the doctrine of informed consent above the requirement that the medical practitioner acts in accordance with the duty of care. This means that patient free choice is respected regardless as to whether her choice leads to a decline in her best interests, since to disrespect patient choice would be an instance of 'unwarranted' paternalism.

This thesis defends the claim that in cases where patient consent comes into conflict with her best interests, paternalistic interference is in fact justified. The ambition of the thesis is thus twofold: in the first place I argue that the doctrine of informed consent cannot be used as an ethical guarantor for medical decision making. Secondly I will conclude that hard paternalism is justified in medical practice, thereby calling for a reversal of the prioritisation of informed consent procedures over the medical practitioner's duty of care.

*For my parents*

## **ACKNOWLEDGEMENTS**

First and foremost I would like to thank my excellent supervisors, Heather Widdows and Iain Law, for providing me with the intellectual engagement and encouragement needed for me to finish this work (even if they often both disagreed as to whether or not my arguments worked). I was incredibly lucky to have both of them as supervisors and so to have insight into my work from both normative and applied angles.

I received invaluable comments on elements contained within this thesis from participants at the 3<sup>rd</sup> CEU graduate conference (2010), the 10<sup>th</sup> World congress of Bioethics (2010) and the Joint Sessions (2011), and would like to thank you all for helping me develop my arguments. My work was also helped greatly with feedback given to me by members of the Department of Philosophy at the University of Birmingham during various graduate seminars. In particular I would like to thank Kirk Surgener, not only for his interesting opinions, but also for abruptly setting me straight when I lost confidence in my work.

I wish to offer my thanks to the AHRC who provided funding for this research, without which this work would not have been possible. I am also grateful to the Department of Philosophy at the University of Southampton for giving me a job during the final stages of writing my thesis when my funding ran out.

Finally, I want to thank Philip for motivating me when I lost interest, supporting me when I was worried, and for cooking me dinner when I was hungry. Thanks, love!

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## INTRODUCTION

When is a medical practitioner morally justified in performing a medical procedure on her patient? Two responses are traditionally given to this question. Firstly, it has been argued that medical procedures are morally permissible when the patient has consented to the intervention. The use of consent as an ethical guarantor in medical decision making is captured by the doctrine of informed consent. Secondly, it can be argued that a medical intervention is morally justified when it is recognised as being in the patient's best interests.

Significantly, these two responses can often come into conflict in medical practice since it is possible for a patient to consent to or refuse treatment which consequently leads to a decline in her best interests. Standardly, such conflicts are resolved by prioritising the doctrine of informed consent above the duty of care. This means that patient free choice is respected regardless as to whether her choice leads to a decline in her best interests, since to disrespect patient choice would be an instance of 'unwarranted' paternalism.

The motivation for this thesis is to provide an alternative resolution to the conflict between respect for patient free choice and the goal of medicine to protect patient best interests. This is achieved by providing reasons to reject the doctrine of informed consent and by mounting a defence of hard paternalism. The ambition of the thesis is thus twofold: in the first place I will argue that the doctrine of informed consent cannot be used as an ethical guarantor of medical decision making. Secondly I will conclude that hard paternalism is in fact justified in medical practice.

I begin in chapter 1 by providing an overview of the development of informed consent procedures within both medical research and therapeutic practice. I outline the transition from the traditional ethics of medicine to protect patient best interests as preserved by the 'duty of care' to the current form of medical ethics and its emphasis on the need to respect patient free choice. This is achieved by drawing upon historical atrocities and various ethical justifications for the presence of informed consent procedures in medical settings.

Informed consent procedures only apply to patients who are competent to make medical decisions. In chapter 2 I present an account of issues surrounding the determination of patient competence. I will show that, with regard to a risk related standard of competence, it is impossible to determine whether someone is competent to make a medical decision in a way that respects patient free choice. I will show that the determination of patient competence is thus in tension with the purpose of informed consent.

In chapters 3, 4 and 5 I provide a detailed analysis of the nature of free choice in order to assess the central justification for informed consent procedures. In chapter 3 I develop my own analysis of what is involved in exercising free choice, drawing upon concepts of de jure liberty, de facto liberty, freedom of action and the capacity for autonomy.

In chapter 4 I expand upon the nature of autonomy as a capacity. I argue that neither minimal nor procedural accounts of autonomy as a capacity suffice to explain why free choices should be respected in medical practice, since it is not possible to determine

whether or not an individual has autonomy as a capacity, and so whether she is capable of exercising free choice. On the basis of my rejection of these accounts I argue that only a substantive account of autonomy as a capacity can be used to explain why free choices should be respected under the doctrine of informed consent.

On the basis of my account of exercisable free choice and my substantive account of autonomy as a capacity, in Chapter 5 I provide an account of absolutism: the position that patient free choices should be respected above and beyond all other ethical considerations. Chapters 6 and 7 constitute rejections of absolutism. In chapter 6 I provide a thought-experiment based on possible absolutist worlds. I use this device to argue that the intrinsic and instrumental goods that are claimed to be protected by absolutism are poorly protected in possible absolutist worlds. This conclusion is used for rejecting the model of absolutism that is adopted by proponents of the doctrine of informed consent.

Subsequently, in chapter 7, I assess and reject the claim that the patient is the best judge of the nature of her best interests. My methodology is to evaluate accounts of well-being, defining the medical decision that is in the patient's best interests as the one that is most likely to protect or improve the patient's overall well-being. Two cases in which it is plausible that the patient is best placed to judge the nature of her best interests are the hedonic mental state account and the actual desire satisfaction account. However, I reject both of these accounts on the basis that they fail to provide a suitable account of best interests in the context of medicine. Within this chapter I also reject informed desire accounts and defend an objective list account of patient best interests.

In chapters 8 and 9 I present an alternative account of medical decision making in the form of hard paternalism. The justification for this account is drawn from the conclusions in previous chapters. In chapter 8 I outline the different forms paternalism can take, both soft and hard. I develop my own criteria of paternalism and then use this definition to assess and reject four theories of justified hard paternalism. Finally, in chapter 9 I present my positive theory of justified 'real hard paternalism' and defend it against possible objections.

## CHAPTER 1: THE DEVELOPMENT OF INFORMED CONSENT

Traditionally, the aim of therapeutic medicine has been the protection and the promotion of the patient's health.<sup>1</sup> The goal of protecting and promoting patient health within medical practice can be traced back to the Hippocratic Oath – an historical oath taken by medical practitioners in order to ensure ethical medical practice. Indeed, historically doctors believed that: "...it was primarily their responsibility to sort out what would be best for patients without necessarily involving them in the choices" (English et. al, 2004: 25).

In the classical version of the Hippocratic Oath, medical practitioners agree that:

[They] will apply dietetic measures for the benefit of the sick according to [their] ability and judgment; [they] will keep them from harm and injustice. [They] will neither give a deadly drug to anybody who asked for it, nor will [they] make a suggestion to this effect...Whatever houses [they] may visit, [they] will come for the benefit of the sick (Hippocratic Oath, Classical Version).

The classical version of the Hippocratic Oath thus requires medical practitioners to 'benefit the sick' and to 'keep them from harm.' Specifically – given the remit of medicine - the medical practitioner is required to benefit the sick patient by improving her health, and prevent harm coming to the patient by protecting her health.

Traditional medical ethics can be seen as being unconcerned with seeking consent from patients. Indeed, the Hippocratic Oath makes: "...no reference to physicians' obligations

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<sup>1</sup>The concept of health is controversial and has been variously analysed as value-neutral biological functioning (Cassell, 1977: 18), value-laden biological functioning (Pellegrino and Thomasma, 1988: 43), and as a phenomenological lived experience (Carel, 2007). In this section I understand health as: "...normal functioning, where the normality is statistical and the functions biological" (Boorse, 1977: 542). My reason for adopting this account of health is simply due to the limited space to discuss the current debate.

to converse with patients” (Katz, 2002: 4) but rather focuses on the doctor’s duty to protect the health of their patients. Traditionally, a medical practitioner’s authority was left largely unquestioned, as patients: “...were simply not deemed qualified to participate in the formulation of ethical behaviour within the profession” (Wolpe, 1998: 39). Lay persons were thus thought to lack the ability to make decisions regarding their health care since they lacked the highly intellectual medical knowledge required to form an appropriate judgement about their health (Wolpe, 1998: 39).

In the current era of medical ethics the requirement that medical practitioners ‘benefit the sick’ and ‘keep them from harm’ is instantiated in the *duty of care*. Although the duty of care is not explicitly formalised, elements of the duty can be drawn from various codes of practice. According to the General Medical Council (GMC) doctors must make the *care* of the patient their concern (English et. al, 2004: 15). The Nursing and Midwifery Council (NMC) states that the ‘first concern’ of nursing is the provision of care and that this achieved by protecting and promoting the health of the patient (NMC, 2008). Likewise, the International Code of Ethics for Nurses (ICN) states that one of the fundamental responsibilities of a nurse is: ‘...to promote health, to prevent illness, to restore health and to alleviate suffering’ (ICN, 2006). Medical practitioners are thus still required to ensure that their patient’s health is protected and promoted.

Over time the goals of medicine have shifted to include respect for the patient’s free choice regarding her medical treatment in addition to the medical practitioner’s duty to care for the patient. The current legal standards in medical ethics require that as well as adhering to the duty of care, doctors must also: “...respect the rights of patients to be

fully involved in decisions about their care” (English et. al, 2004: 15).<sup>2</sup> The increasing demand to respect patient free choice is captured by the development of informed consent procedures in both medical research and therapeutic practice.

Here I will provide an account of how the doctrine of informed consent developed within an historical context (section 1.1) both in terms of medical research (section 1.1.2) and therapeutic medicine (section 1.1.3). In order to gauge why the doctrine of informed consent has become ethically significant it is also useful to look at its ethical justification. In section 1.2 I therefore address two ethical justifications for the practice of informed consent, including the moral demand to respect patient free choice (section 1.2.1) and the legal requirement to carry out informed consent procedures (section 1.2.3). On the basis of this exposition I will explain how it is possible for respect for free choice (as protected under the doctrine of informed consent) to come into conflict with the medical practitioner’s duty to act in the patient’s best interests (section 1.3).

The purpose of this chapter is to provide the groundwork for developing the dual purposes of my thesis, specifically that informed consent cannot be used as an ethical guarantor of medical decision making and secondly that the prioritisation of the duty of care and the position of hard paternalism can be justified in medical practice; by explicating the historical and ethical motivations for informed consent procedures, and how such procedures come into conflict with the medical practitioner’s duty to protect

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<sup>2</sup> The GMC’s guidelines for doctors are extensive including ‘keeping professional knowledge up to date’, ‘recognising limits of professional competence’, ‘being trustworthy’ and ‘treating information confidentially’ (English et, al., 2004: 15). Here I narrow my focus on the GMC’s emphasis on the duty of care and respect for patient choices given that this is the scope of my thesis.

patient best interests, I provide the theoretical foundation for arguing for a reversal of the prioritisation of informed consent above the duty of care.

### ***1.1 THE HISTORICAL DEVELOPMENT OF INFORMED CONSENT***

The doctrine of informed consent has become ethically significant in medical practice and research in response to a number of atrocities in medical research and case law. These have included Nazi war experiments (1939-1945), the Porton Down scandal in Britain (1950s and 1960s), the Tuskegee syphilis study (1932-72) and the Willowbrook State school study (1956-70). In the following I will indicate how these atrocities led to a movement away from the traditional model of simple consent (section 1.1.1), to a developed concern for informed consent in both medical research (section 1.1.2) and therapeutic medicine (section 1.1.3).

#### ***1.1.1 Traditional Medical Ethics and Simple Consent***

Prior to the establishment of informed consent the duty of care was buffered by a model of 'simple consent' (Grisso and Appelbaum, 1998: 5), an ancient legal requirement for surgical interventions for both experimental treatment and therapeutic purposes (Katz, 2002: 49; Wolpe, 1998: 51). Simple consent is present when a patient agrees to medical treatment; this is the case regardless as to whether or not the patient knows or understands the nature of the procedure she is consenting to. Although simple consent was aimed at protecting patients from being treated against their will, explicit consent was not required. Instead, simple consent was taken as being implied if the patient did not clearly object to the treatment on offer (Grisso and Appelbaum, 1998: 5). Simple

consent was thus thought to legitimise the medical practitioner's interference with the patient's health without the medical practitioner needing to inform the patient of the nature, risks or purpose of the treatment.

The earliest record of simple consent in English law can be traced back to 1767 with the case *Slater v. Baker and Stapleton*. The plaintiff in the case, Slater, hired his doctors to remove the bandages from a partially healed leg fracture. Against Slater's protests the doctors then re-fractured his leg and placed it in an experimental apparatus (Faden and Beauchamp, 1986: 116). Slater sued his physicians for battery for undertaking unwanted treatment - namely breaking his leg - over and against his objections (Grisso and Appelbaum, 1998: 4). The doctors were successfully sued for battery since they had failed to obtain their patient's simple consent. Indeed, the patient's explicit objections to the procedure countered any presumption they may have had that the patient consented to the treatment. As highlighted by the Slater case, previous to the implementation of informed consent in medical law: "[p]hysicians could be, and were, sued for battery when they undertook treatment over patients' objections" (Grisso and Appelbaum, 1998: 5). Thus historically, although medical practitioners were not required to inform their patients of the nature of the treatments available to them or the nature of their medical problem, the patient could refuse medical treatment under the principle of simple consent.

### ***1.1.2 Informed Consent in Research***

An important factor leading to the transition from 'simple' to 'informed' consent were cases of medical malpractice in the domain of medical research. Indeed, many commentators have pointed to Nazi atrocities and the abuse of research subjects in both Europe and the United States as spearheading the move from simple consent to informed consent law (Faden and Beauchamp, 1986: 87). The doctrine of informed consent thus: "...has its origins in the experience of moral suffering and moral outrage caused by moral abuses" within medical research (Reich, 1996: 83). Some of the key 'moral abuses' referred to in the increasing interest in informed consent are Nazi war experiments (1939-1945), the Porton Down scandal in Britain (1950s and 1960s), the Tuskegee syphilis study (1932-72) and the Willowbrook State school study (1956-70) in the United States. As I will show, each of these events in medical research led to the development of ethical codes safe-guarding the practice of informed consent in the western world.

Schmidt claims that the British Medical Research Council accepted the use of informed consent for medical research on humans as early as 1945 (Schmidt, 2006: 369). Indeed, discussions on the ethics of human experimentation in the 1930s advised that: "...the risk of a criminal charge against the MRC [Medical Research Council] was so remote as to be negligible if the patient had given his full consent and if all the risks of the experiment had been explained" (Schmidt, 2006: 369). Early demands for informed consent were thus based on the risk of the medical researcher being prosecuted. However, the development of informed consent procedures in medical research as a means of respecting individual free choice is more commonly attributed to the

Nuremberg Code (1949). The Nuremberg Code, which was developed in response to medical atrocities committed during WWII, was indeed crucial to introducing the concept of informed consent into the domain of medical research (Faden and Beauchamp, 1986: 153). During WWII Nazi scientists researched: "...the effects of ingesting poisons, intravenous injections of gasoline, immersion in ice water, and the like" on human subjects (Faden and Beauchamp, 1986: 153). They also carried out medical experiments which involved infecting human subjects with epidemic jaundice and spotted fever virus (Faden and Beauchamp, 1986: 153). Such experiments on human subjects undertaken by the Nazis during WWII "...seriously undermined the reputation of medical practice and [...] damaged doctor-patient relationships" (Schmidt, 2004: 265).<sup>3</sup> The discovery of the abuses of medical research led to the demand that research subjects should be protected against any possible future misconduct in medical research.

In order to explain what was wrong with the Nazi research<sup>4</sup>, a 10-point medical code was issued specifying some of the: "...the human rights of patient-subjects and the duties of physician-researchers for experiments on humans" (Schmidt, 2006: 369). The Nuremberg Code (1949), an international medical code governing the ethics of medical research, explicitly adopts the doctrine of informed consent, stating that:

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<sup>3</sup>Although the development of informed consent is partially attributed as a response to Nazi eugenics, the practice of eugenics was in fact historically much more widespread. For a detailed history of eugenics see: Garver and Garver, 1991 and Kevles, 1985.

<sup>4</sup> Each of the medical research scandals addressed here can be criticised on grounds beyond the lack of informed consent. Other factors monitoring the ethics of medical research include protecting the welfare of the individual, informing other health care professionals that the research is being carried out and that justice is considered in relation to vulnerable groups (English, et. al., 2004: 492). The ethical problem with these instances of medical research thus includes the absence of informed consent but is not reducible to it. My focus, however, will be on the absence of informed consent and how this has been used to criticise instances of research malpractice and develop the doctrine in both research and therapeutic settings.

The voluntary consent of the human subject is absolutely essential. This means that the person involved [in research] should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonable to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment (Nuremberg Code, 1949).

Although the Nuremberg Code does not refer to the term 'informed consent' it stipulates its requirements. Indeed, the code demands that the consent of the potential research subject is 'essential' and that she should have 'sufficient knowledge and comprehension of [...] the nature, duration and purpose of the experiment.' The demand of the code to obtain the consent of human research participants who have been informed of the nature and risks of the experiment encapsulates the basic requirements of the doctrine. Unlike the traditional model of simple consent, which presumed the consent of patients unless it was explicitly refused, the Nuremberg code also emphasises the importance of the *voluntary* consent of its research subjects. Under the code, the consent of the patient could no longer be presumed, but had to be freely given so that it is not: "...based on force, fraud, deceit, duress, constraint, or coercion, and the like" (Manson and O'Neill, 2007: 16-7). The Nuremberg code thus contributed to a transition from simple to informed consent (O'Neill, 2002: 48).

However, although the Nuremberg code stipulated that the voluntary, informed consent of the research subject was required, and the British Medical Research Council had recommended that “full consent” was needed for human experimentation as early as 1945, the doctrine was often ignored. Specifically, the doctrine was not implemented during the Porton Down (1950s and 1960s) and more recently Alder Hey (1988-95) scandals. At the Porton Down military science park scientists secretly tested nerve gas and chemical warfare on thousands of soldiers. The research was – in part – objected to on the basis that: “...the soldiers had only partial, if any, knowledge about the precise nature of the experiments and that they were not fully informed about the risks involved” (Schmidt, 2004: 277). The lack of informed consent was thus still an issue in medical research ethics during the middle of the twentieth century.

Towards the end of the twentieth century it emerged that “...various whole organs including hearts and brains, had been removed at necropsy from children at Alder Hey Hospital in Liverpool without the knowledge and consent of parents (Bauchner and Vinci, 2001: 309). As recently as 2001 British law has been attempting to strengthen informed consent requirements in response to the failure of Alder Hey to obtain informed consent from parents, leading to the development of The Report of The Royal Liverpool Children’s Inquiry. The Inquiry reiterates that: “...fully informed consent is required and nothing less. Fully informed consent must be freely given without imposition of pressure” (The Report of The Royal Liverpool Children’s Inquiry: 2001, 1.1). They further state that fully informed consent requires that: “...a person must have all the information required to form a final decision” (The Report of The Royal Liverpool Children’s Inquiry: 2001, 1.3).

The doctrine of informed consent also developed in response to recent cases of medical malpractice in research in the United States through the development of the Belmont Report (1979). In the Tuskegee syphilis study (1932-72) physicians monitored 600 black men, 400 of whom had syphilis, without treatment, over a period of 40 years, in order to observe the natural course of the disease (Baron, 2006: 12). The men were never informed that they were subjects in a large-scale and long-term study, and nor were they told that they were suffering from syphilis (Schmidt, 2004: 284). The public shock that so many individuals were part of this medical research without their knowledge demanded more stringent ethical codes of medical practice, it being referred to as: "...one of the greatest medical ethics scandals in American history" (Schmidt, 2004: 284).

During a similar period of time, physicians working in the United States at the Willowbrook State School (1956-70) were carrying out medical research on children without the informed consent of their guardians. According to Reich, physicians working at the Willowbrook institute for severely mentally retarded children attempted to develop an effective prophylactic against hepatitis. In order to proceed with this study: "...the medical staff deliberately infected newly admitted patients with isolated strains of the virus, for a total of seven to eight hundred children" (Reich, 1996: 83-4). When the wider public and government became aware of the scandal, it was regarded as requiring an official codification of the doctrine of informed consent because the consent forms that had been supplied to parents were misleading and parents had been threatened that their children would not be admitted to the hospital unless they gave their consent for their children to undertake the treatment (Reich, 1996: 84).

Such atrocities in America were integral to the development of Belmont Report (1979), which like the Nuremberg code aimed to protect the human research subject. According to the Belmont report, informed consent requires that research subjects are: “...given the opportunity to choose what shall or shall not happen to them [...] the consent process can be analyzed as containing three elements: information, comprehension and voluntariness” (Belmont Report, 1979: Section C1). Given the ignorance of the participants of the Tuskegee syphilis study and the coercion involved in the Willowbrook scandal, the Belmont report emphasises the importance of comprehension and voluntariness in informed consent procedures.

More recently (1964-2008) the Declaration of Helsinki has made similar demands for informed consent in medical research. Developed by the World Medical Association (WMA), the Declaration of Helsinki is a statement of ethical principles for medical research involving human subjects and devotes significant space to outlining the demands of informed consent:

In medical research involving competent human subjects, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail, and any other relevant aspects of the study. The potential subject must be informed of the right to refuse to participate at any time without reprisal. Special attention should be given to the specific information needs of individual potential subjects as well as to the methods used to deliver the information. After ensuring that the potential subject has understood the information, the physician or another appropriately qualified individual must then seek the potential subject's freely-given informed consent, preferably in writing. If the consent cannot be expressed in writing, the non-written consent must be formally documented and witnessed (Declaration of Helsinki, 2008: Section B24).

The declaration requires medical researchers to obtain informed consent from their potential research subjects by informing them of all relevant aspects of the study and of their right to refuse to participate. Unlike the Nuremberg Code, the Declaration also requires that the research subject's consent is explicitly documented and that the information is presented to the patient in light of her specific communicative needs. Rather than simply *presenting* information to the potential research subject, the declaration demands that: "...the research subject *grasps* what is proposed and the likely risks involved in the research (Manson and O'Neill, 2007: 8). Thus, in current medical research practice a very strict form of informed consent is required, since the research subject must be informed of and actually grasp:

1. the purpose of the research
2. the method(s) used, and
3. the likely risks, immediate and projected
4. the sources of funding
5. possible conflicts of interest
6. the intended benefits of the research
7. any other relevant aspects of the study<sup>5</sup>
8. the subject's right to withdraw consent

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<sup>5</sup> The 'relevant aspects' required by condition (7) must be restricted to the broad aims of the study, since the requirement that the potential participant be informed of *any* information relevant to the study is too demanding – for instance, it would be impracticable to require that each participant understood the intricacies of the scientific methods used to carry out the research. In this vein, UK Biobank requires only that the potential participant is informed of the broad aims, purpose and nature of the research (UK Biobanks Ethics and Governance Framework, 2007: B1), reasonably limiting condition (7).

As it stands, medical research upon a subject is considered ethical just so long as the patient is informed in terms of conditions 1-8 and she offers her consent.

### ***1.1.3 Informed Consent and Therapy***

Not only can the development of the doctrine of informed consent be historically traced in the domain of medical research, the practice of informed consent also became important in therapeutic practice throughout the nineteenth and twentieth centuries. One factor which led to the change in therapeutic law was the move towards informed consent procedures in medical research. This is the view of Manson and O'Neill who claim that the transformation of medical ethics on the level of research simply continued to grow in therapeutic settings by seeking: "...to protect patients by requiring their consent for all medical interventions" (Manson and O'Neill, 2007: 4). The implementation of informed consent in therapeutic contexts is thus thought by some to be a consequence of its instantiation in research practices since it was only after the introduction of the doctrine in codes of medical research that it emerged as being central to clinical practice (O'Neill, 2002: 19).

However, others have suggested that it was the legal profession that was at the forefront of the interest in informed consent in therapeutic practice (Faden and Beauchamp, 1986: 88). Actual use of the term 'informed consent' in therapeutic practice appears to have been introduced into medicine via American case law in the landmark case of *Salgo v. Leland Stanford Jr. University Board of Trustees* (1957) (Faden and Beauchamp, 1986: 101). In this case, Martin Salgo brought his physicians to court after suffering permanent

paralysis as a result of a translumbar aortography, suing them for their negligence and failure to warn him of the risk of paralysis (Faden and Beauchamp, 1986: 125). Justice Bray ordered on the basis of *Salgo* that physicians had an explicit duty to disclose certain forms of information and then to obtain the consent of their patient, using the expression 'informed consent' (Katz, 2002: 60). The doctrine of informed consent, as used in case law is thus attributed to the *Salgo* case, since it shifted the main goal of medicine from the duty of care to informed consent and the need to respect patient free choice (Wolpe, 1998: 51). Moreover, *Salgo* also focused on the problem of whether the consent had been informed when given (Faden and Beauchamp, 1986: 126).

The doctrine of informed consent as applied to therapeutic practice in the UK has been codified in the guidelines of the Department of Health:

[p]atients have a fundamental legal and ethical right to determine what happens to their own bodies. Valid consent to treatment is therefore absolutely central in all forms of healthcare, from providing personal care to undertaking major surgery (Department of Health, 2001: 9).

Again, although here there is no explicit mention of *informed consent*, the guideline does state that:

The provision of information is central to the consent process. Before patients can come to a decision about treatment, they need comprehensible information about their condition and about possible treatments/investigations and their risks and benefits (including the risks/benefits of doing nothing) (Department of Health, 2001: 17).

The requirement that doctors ensure that their patients are informed of and understand the benefits and risks associated with the variety of therapeutic options available to them is in the appropriate sense, demanding a standard of informed consent.

A concise summary of the doctrine as put into therapeutic practice is also provided by the NMC's code of practice for Nurses and Midwives:

[1] You must ensure that you gain consent before you begin any treatment or care. [2] You must respect and support people's rights to accept or decline treatment and care. [3] You must uphold people's rights to be fully involved in decisions about their care. [4] You must be aware of the legislation regarding mental capacity, ensuring that people who lack capacity remain at the centre of decision making and are fully safeguarded. [5] You must be able to demonstrate that you have acted in someone's best interests if you have provided care in an emergency (NMC, 2008: 3-4).

Here the obtaining of consent includes a requirement that the patient has capacity to make a medical decision [4]<sup>6</sup>. If the patient meets this condition then the patient should be *fully involved* in the decision making process [3], observing the right to refuse any medical treatment or care the nurse offers [2]. However, if the patient lacks competence then the Nurse is required to act in accordance with the duty of care [5].

The doctrine of informed consent can be seen as developing within both medical research and therapeutic medicine, not only as a response to atrocities within medical research but also as a response to controversies within case law.<sup>7</sup> Taken together,

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<sup>6</sup> "The terms mental 'capacity' and 'competence' are often used interchangeably in medical ethics, although the former is most often used in law" (English et. al., 2004: 74). The relevance of capacity (referred to in this thesis as competence) will be explored in greater depth in Chapter 2.

<sup>7</sup> The change in the therapeutic setting can also be connected with the various civil-rights movements occurring during the middle of the twentieth century. As Schmidt notes: "The growing public awareness of

informed consent procedures emerged in response to such scandals and became the dominant ethical practice in medical research and therapeutic medicine. As I will show in the following section this change is primarily justified by identifying ethical medical practice with patient or subject free choice.

## ***1.2 ETHICAL JUSTIFICATIONS FOR INFORMED CONSENT***

There are two main justifications for informed consent procedures: (1) respect for patient free choice (section 1.2.1) and (2) legal necessity (section 1.2.2). Whilst the central justification for informed consent has been (1) the importance of respecting patient free choice, the relevance of (2) should not be underplayed when considering the advantages that informed consent procedures provide for medical practitioners. In the following, I present some of the main defences of each of these justifications.

### ***1.2.1 Respect for patient autonomy and free choice***

A central justification for informed consent procedures is the importance of respecting patient autonomy (Manson and O'Neill, 2007: 17). Throughout the 1980's, it was thought that the demand for informed consent was: "...justified almost exclusively under the principle of autonomy" (Appelbaum et. al, 1987: 22) it being recognised as the "...primary justification of informed consent provisions" (Beauchamp and Childress,

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civil rights and democratic values called for a reevaluation of doctor-patient relationships, and for a reassessment of the duties that experimenters had towards their patient-citizens" (Schmidt, 2004: 281). The civil-rights activists were demanding increased rights to make informed decisions in other aspects of life (Faden and Beauchamp, 1986: 101). This general attitude can help explain the change in legal thinking, accounting for the patients' rights movement: "...as well as for the bioethical movement in general" (Viafora, 1996: 11).

1989: 75). The significance of this justification is evident in Dworkin's claim that "[a]ll discussions of the nature of informed consent and its rationale refer to patient (or subject) autonomy" (Dworkin, 1988: 5) and O'Neill's observation that: "...demands that medical professionals respect autonomy and rights have become a constant refrain" (O'Neill, 2002: 4). More recently, Manson and O'Neill have recognised that: "[t]he reason most commonly given for the expansion, entrenchment and elaboration of informed consent requirements is that they are needed to secure respect for individual autonomy" (Manson and O'Neill, 2007: 185). Respect for patient autonomy is thus a central justification for the implementation of informed consent procedures.

Problematically, the concept 'autonomy' is vague and has various meanings in different contexts. As Faden and Beauchamp have noted, the term has been loosely associated with ideas as diverse as: "...privacy, voluntariness, self-mastery, choosing freely, the freedom to choose, choosing one's own moral position, and accepting responsibility for one's choices" (Faden and Beauchamp, 1986: 7). Furthermore, the concept has also been used to bear connotations with freedom, independence and self-determination (Schermer, 2002: 1).

However, although moral philosophy has conceptualised autonomy in a variety of ways, in medical ethics patient autonomy is assumed to be protected by respecting patient consent or free choice: "[the] assumption that ethics is served if autonomy is respected and that this is done by a fully informed choice (to consent or not), underlies the majority of bioethical practice" (Widdows, 2011: 88). In extremely broad terms, the ethical basis for informed consent procedures is that patients are capable of leading

lives as they choose and so they should not be constrained by the beliefs and values of others. For this reason it is claimed that their free choice to refuse or consent to treatment should be respected.

Joseph Fletcher is attributed with first venturing the idea that autonomy is the highest moral value within medical ethics (Callahan, 1984: 28). In his seminal work, *Morals and Medicine* (1955), Joseph Fletcher argues that patients have a moral right to choose or refuse treatment, since: “[w]ithout their freedom to choose and their right to know the truth, patients are only puppets” (Fletcher, 1955: 33). Furthermore, Fletcher argues that if persons are not permitted to choose for themselves but are instead subject to the paternalism of doctors, patients are not treated as: “...moral agents or personal beings” (Fletcher, 1955: 35). Because patients are persons and moral beings, their moral integrity depends upon: “...first, freedom of choice, and second knowledge of the facts and of the course between which we may choose” (Fletcher, 1955: 35). The right to autonomy as protected by the doctrine of informed consent is thus argued by Fletcher to protect the moral dignity of what it means to be a person.<sup>8</sup>

It is commonly argued that it is important to respect free choices because people have a privileged right to freely choose what to do with their lives (Savulescu, 2003). On this view it is held that the individual is the sovereign authority over her ‘bodily domain’ and may freely choose what happens *to* and what she does *with* her body even if such

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<sup>8</sup> Fletcher explains the ethical value of respecting autonomy in terms of human dignity. Within my thesis I leave issues as to the nature of human dignity to one side due to a limitation of space and because, as shown, the central explanation of the value of autonomy in the current informed consent literature is the importance of respecting free choice. I explore various alternative explanations of the value of free choice in Chapter 6.

behaviour is detrimental to her overall well-being: when such choices are autonomous they *morally ought never to be overridden* (Faden and Beauchamp, 1986: 19). Since the individual owns her body it is claimed that freely given consent to the use of that body is sufficient for rendering that use ethical (Feinberg, 1986: 56).

An important justification for informed consent procedures is thus to respect patient autonomy and this is achieved by respecting the patient's free choices. Since failing to respect a patient's choices on the grounds of well-being or risk fails to respect their choices, and thereby fails to respect their autonomy, such interference is argued to be unethical. Informed consent is thus perceived as a way of ensuring that medical research and therapeutic practice are carried out ethically since it requires maximal respect for patient free choices and thereby respects patient autonomy.

### ***1.2.3 Legal necessity***

Although reliance upon the demand to respect individual autonomy as a justification for informed consent is commonplace (a central premise that this thesis contests) it is important to note that there also exist less widely supported justifications; as Faden and Beauchamp have noted: “[w]hether the principle [of respect for patient autonomy] is the exclusive or even the primary justification of consent requirements is controversial” (Faden and Beauchamp, 1986: 9).

Manson and O’Neill argue that informed consent procedures can only be successfully justified on the basis of legal necessity. The pair note that it is the *nature* of medical

practice to carry out procedures that would normally infringe upon an individual's human rights.<sup>9</sup> Informed consent permits a doctor to carry out actions that would usually be illegal or unethical and so: "...is a way of justifying action that would otherwise violate important norms, standards or expectations" (Manson and O'Neill 2007: 75). For example, under ordinary circumstances an individual is protected in law from having his or her blood extracted by another individual; this would normally constitute a battery or an assault. In the medical arena, however, it is sometimes necessary for doctors to extract blood for diagnostic purposes. In order to prevent such medical procedures being classified as battery or assault, the patient can consent to her blood to be taken without criminal or legal repercussions. Importantly, without the patient's consent the doctor will be breaching ethical norms and laws by acting against the will of the patient or research subject (Manson and O'Neill, 2007: 76). Furthermore, if the patient waives his or her rights within the medical setting then the doctor is no longer in a position of liability, since as Davis points out: "crimes and torts may not be committed if a person properly consents to an interference which would otherwise be unlawful" (Davis, 2003: 368). Hence, in addition to protecting patients from unauthorised physical invasions, informed consent is claimed to be ethically justified since it prevents physicians from being prosecuted for what would otherwise be criminal acts and the necessity of waiving certain rights and legal requirements in order for medical procedures or research to take place.

In this section I have shown that there are two ethical motivations for seeking consent in medical practice. Firstly I have shown that a central justification for informed consent

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<sup>9</sup> The following discussion of Manson and O'Neill's theory of the justification for informed consent is adapted from my article (Bullock, 2010: 540-41)

procedures is to protect the patient against unwanted interference equating respect for autonomy with respect for free choice. Secondly, the practice of informed consent is justified out of legal necessity in order to prevent doctors from being prosecuted for malpractice under laws of battery and assault.

### ***1.3 THE CONFLICT BETWEEN FREE CHOICE AND PATIENT BEST INTERESTS***

Although the historical progress of informed consent in both areas of therapy and research indicate that it is an important element of ethical medical practice, the implementation of the doctrine has been met with great pessimism. Some have argued that paternalism is prominent in medical practice and doctors simply pay lip service to the doctrine of informed consent (Katz, 2002), whilst others argue that the high standards of informed consent can never be reasonably met (O'Neill, 2002).

However, the main problem that will be focused on in my thesis is that the free choice to refuse treatment by competent patients is often antithetical to the demand to protect and promote the patient's health under the duty of care. This is quite simply because a patient may freely choose or refuse treatment that leads to a decline in her health. Such cases are present with patients who base their medical choices on the basis of religious values. For instance, cases in which blood transfusions are refused by Jehovah's Witnesses exemplify the rejection of medical treatment on the basis of personal religious values which lead to a (sometimes fatal) decline in the patient's health. The duty to protect the health of the patient and the duty to respect the competent patient's free choices thus pull in opposite directions in the process of medical decision making

when the individual chooses to shape her life in accordance with values aside from that of protecting her health.

The tension between respect for the competent patient's free choice and the duty of care can be resolved by prioritising either of these ethical demands. Whilst the prioritisation of the duty of care would constitute a paternalistic dismissal of the patient's free choice, placing the ethical demands of the doctrine of informed consent above that of the duty of care permits patients to make harmful or imprudent medical decisions. This tension is currently resolved by claiming that the doctrine of informed consent is of greater ethical importance than the duty of care, it being claimed that if a patient is competent, then her free choices: "...morally ought never to be overridden by considerations of beneficence or proper care" (Faden and Beauchamp, 1986: 19). Whilst the importance of the duty of care is acknowledged, the function of medicine is thought to be to respect autonomy, the preservation of life being subservient to this 'primary goal' (Cassell, 1977: 18).

Patients are thus claimed to have a 'moral warrant' for rejecting treatment that would be beneficial to their health (Beauchamp, 2003: 271). Given that the doctrine of informed consent is argued to be more ethically important than the duty of care, medical practitioners are required to respect the free choices of their patients *even if* they regard such choices to be imprudent, harmful or dangerous to the patient's health.

Rather than being seen as a competing ethical demand, respect for free choice could be *subsumed* under the duty of care. This ordering of ethical frameworks could thus be explained in two ways: either (a) there is greater ethical value in respecting patient free

choice than there is in protecting and promoting her best interests, or (b) the protection of the best interests of the patient is manifested by respecting her free choices. This is a subtle, yet important, distinction – in the former case a patient’s decision can be conceptualised as conflicting with her best interests. In the latter instance a patient’s choice will *constitute* what is in her best interests, *even if* the choice is regarded by others to be risky or harmful. My evaluation of the prioritisation of informed consent will play on this nuance: in chapter 6 I reject the prioritisation on the basis of the assumption that (a) there is greater ethical value in respecting patient free choice than there is in protecting and promoting her best interests, whilst in chapter 7 I undermine the claim that (b) the protection of the best interests of the patient is manifested by respecting her free choices by providing my own account of best interests.

#### **1.4 CONCLUDING REMARKS**

A variety of factors have led to the adoption of informed consent in modern medical practice. Although the duty of care has a long history within medicine, the right of the patient to be informed about her medical treatment and respect for her consent developed more recently in response to a number of moral atrocities, leading to the development of various ethical codes.

In the domain of research informed consent law was developed in order to protect human subjects from harm. The abuse of medical authority and trust led to the formulation of ethical codes intended to protect the individual’s interests in self-determination. Informed consent thus became important in medical practice: “...because

it can be used to protect research subjects and patients against grave wrongs” (Manson and O’Neill, 2007: 17) and is therefore thought to protect the individual from unwanted interference.

The importance of informed consent subsequently developed within the domain of therapeutic settings. Gradually, the patient was viewed as having a right to be informed about her medical condition and the treatments available to her in order for her to give autonomous and explicit consent in all areas of medicine. An important reason why informed consent is heralded in medical practice is thus because it is required in order to fully respect the autonomy of research subjects and patients (Manson and O’Neill, 2007: 17). Informed consent is viewed as an important means to achieve the ideal of patient autonomy (understood as being protected through respect for free choice) (Schermer, 2002: 24) and as a means of preventing medical practitioners from being sued for medical malpractice.

Moreover, I have shown how informed consent procedures come into conflict with the medical practitioner’s duty to protect patient best interests under the duty of care. This chapter has therefore provided the groundwork for the goal of my thesis to argue for a reversal of the prioritisation of informed consent above the duty of care.

## **CHAPTER 2: COMPETENCE ASSESSMENTS**

As noted in section 1.1.2 the doctrine of informed consent only requires that competent patient free choices regarding medical treatment be respected. Here I outline some of the main features of competence and some of the problems of determining whether they are functioning when a patient makes a decision (section 2.1). Furthermore I explain how competence and incompetence are measured and protected in law (section 2.2 and 2.3). I assess and reject a risk related standard of measuring competence (sections 2.4.1 and 2.4.2) and finally outline some concerns with making medical decisions on behalf of incompetent patients (section 2.5.1). This chapter thereby provides the basis for understanding when informed consent procedures are applied and provides the rough distinction I provide between competent and incompetent patients will be used to explain different forms of paternalism in Chapter 8. Moreover, the concerns I raise against the risk related standard of measuring competence (sections 2.4.1 and 2.4.2) constitute indirect arguments for the adoption of hard paternalism.

### ***2.1 FEATURES OF COMPETENCE***

In order for a patient to offer informed consent and for it to be respected it is necessary to determine whether or not a patient is competent to refuse or consent to medical treatment (section 1.3.1). In standard practice the competence of a patient is determined by assessing whether or not the patient has a range of functioning capacities. In the following I present the main capacities required for competence as discussed in the recent literature. This will purely be an exposition of the current debate since it is not within the scope of my thesis to precisely determine the capacities required for

competence, nor to develop a test for competence. Rather, it is useful to briefly explain some of the required capacities for patient competence in order to clarify the distinction between competent and incompetent patients used in medical practice.

As noted in section 1.3.1 determining patient competence is important to the implementation of the doctrine of informed consent, since the doctrine stipulates that the patient has a right to:

...forego treatment or even cure if it entails what for him are intolerable consequences or risks, however warped or perverse his sense of values may be [...] so long as any distortion falls short of what the law regards as incompetency (Abernethy, 1984: 53).

Since the doctrine of informed consent does not come into play unless the patient is competent the medical practitioner must be able to determine the capacities required for competence. As such: "...we cannot say that a person is competent to give informed consent unless we know what capacities are required for the task" (White, 1994: 54).

The MacCAT-T test for patient competence is currently used as guide for medical practitioners and is regarded as the 'gold standard' for determining patient competence in clinical psychiatry (Breden and Vollmann, 2004: 274).<sup>10</sup> The MacCAT-T test measures four separate capacities as a bundle in the assessment of patient competence. According to the MacCAT-T test, the capacities required for competent decision making include:

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<sup>10</sup> Although the MacCAT-T test is intended to provide an assessment of the patient's psychiatric competence, it does not reach conclusions about a patient's legal competence which need to be based upon: "...the medical and social circumstances in which the patient's decision is to be made" (Grisso and Appelbaum, 1998: 173-4).

- a) **Understanding** of treatment-related information, focusing on categories of information that must be disclosed as required by the law of informed consent.
- b) **Appreciation** of the significance of the information for the patient's situation, focusing on the nature of the disorder and the possibility that treatment would be beneficial.
- c) **Reasoning** in the process of deciding on treatment, focusing on the ability to compare alternatives in light of their consequences, including the ability to draw inferences about the impact of the alternatives on the patient's everyday life.
- d) **Expressing a choice** about treatment (Grisso and Appelbaum, 1998: 173 [original emphasis])

Thus, according to the MacCAT-T test, a patient will be competent to refuse or consent to medical treatment if she is able to a) understand information, b) appreciate that information, c) reason with the information, and d) express a choice (Grisso and Appelbaum, 1998: 20).

The capacity to (d) express a choice is perhaps the most straightforward capacity. This is simply the ability to state a choice, or indicate a desire for: "...a professional or other responsible person (e.g., relatives) to make the choice" (Grisso and Appelbaum, 1998: 190).<sup>11</sup> Persons, who are unable to communicate a choice, would fail to meet this capacity for competence.<sup>12</sup>

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<sup>11</sup> For more on surrogate decision making see sections 2.2 and 2.5

<sup>12</sup> This is not to say that certain individuals should not be aided in communicating their choice. Indeed: "[d]octors have a general ethical duty to enhance capacity when it is possible to do so" (English, 2004: 107). For instance, if a patient does not speak English then a translator should be provided. Likewise sign

The capacity to (a) understand information: "...is the most common ability on which legislatures rely and to which judges refer in their competence judgements" (Grisso and Appelbaum, 1998: 38) and encompasses a broad range of skills, including: "...linguistic, conceptual, and cognitive abilities that enable people to receive, process, store and retrieve information" and "...an ability to imagine what life would be like in certain states and conditions" (Wicclair, 1991: 91). A central difficulty with assessing whether a patient understands the information disclosed to her is determining how much information is needed for her to be able to understand the nature of the medical treatment options available to her (Freedman, 1981: 63). The problem with determining how much information is required for a patient to understand the nature of her condition and the risks and benefits associated with particular courses of medical treatment and the difficulty of communicating this information is explored further in section 6.2.1.

A further problem is that it is easy to assess a patient as unable to understand the information presented to her if she then uses that information to reach a decision regarding her medical treatment in an unusual way. Indeed, Grisso and Appelbaum say that we judge that a patient understands the information: "...when they do or say something that we would expect of persons who have assimilated the information as we meant to convey it" (Grisso and Appelbaum, 1998: 41). However, if the capacity for understanding is measured in terms of expected decisions that would be made if a person did understand the information, patient competence will be measured in terms of the perceived reasonableness of the decision, rather than the patient's competence to

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language should be taken as communicative in the case of deaf persons and other means of communication sought for paralysed or disabled persons.

make that decision. As I will show in section 2.4, focus on the decision made by the patient rather than her competence to make the decision is problematic for the adherent of informed consent procedures. If understanding is to be measured as a capacity for competence it must be done in terms of “intellectual comprehension” (Freedman, 1981: 63), rather than in terms of how that information is used to influence the patient’s decision outcome.

According to Grisso and Appelbaum, (b) appreciation of information is similar to (a) the capacity for understanding, but differs in that it requires that the patient applies the information she understands about a medical condition and the various medical procedures available to treat it, to herself, her own condition and her own circumstances. If the patient lacks the capacity of appreciation then she will be found to be incompetent to make a medical decision, indeed: “[c]ourts have recognised that patients who do not acknowledge their illnesses (often referred to as ‘lack of insight’) cannot make valid decisions about treatment” (Appelbaum, 2007: 1836). In order to have the capacity for appreciation the patient must thus realise that she actually has the medical condition and that the benefits and risks of certain treatments or non-treatment in reality apply to her own situation (Grisso and Appelbaum, 1998: 184-5). Notably, in relation to the concern of adherents of the doctrine of informed consent that competence assessments should not be focussed on the outcome of the decision, but rather on whether the patient is competent to make a decision (section 2.4) it has been argued that: “...appreciation focuses on patients’ acknowledgement of the *potential* value of treatment; whether they would actually accept the treatment is not relevant” (Grisso et. al, 1995: 129). Thus, it is claimed, the capacity for appreciation should not be

measured in terms of whether the patient accepts the treatment on offer, but rather that she understands the consequences for herself of refusing or consenting to treatment.

Due to the similarities between the capacities for (a) understanding and (b) appreciation, Buchanan and Brock subsume the capacity for appreciation under the capacity of understanding. They claim that:

[u]nderstanding is not a merely formal or abstract process, but also requires the ability to appreciate the nature and meaning of potential alternatives – what it would be like and ‘feel’ like to be in possible future states and to undergo various experiences – and to integrate this appreciation into one’s decision making (Buchanan and Brock, 1989: 24).

The capacity for appreciation thus expands the capacity for understanding, where the patient understands that the condition and the treatment options apply to her current circumstances: “[a]ppreciation requires the highest degree of understanding...the patient must appreciate the implications of the medical information for his or her life” (Drane, 1985: 20).

However, since appreciation can be interpreted as a deeper form of understanding it is unsurprising that it suffers from the same difficulty of determining how much information is required to be conveyed to the patient in order that she can appreciate the nature of her medical condition. Likewise, if the amount of information determined to be adequate for the assessment of the capacity for appreciation is extensive then the capacity may also be subject to the problem of communication addressed fully in section 6.2.1.

The patient's ability to reason (c) focuses on the reasoning process used to reach a decision. The assessment of this capacity is controversial because a medical practitioner could judge a patient's choice as incompetent simply because she disagrees with the patient's reasons (Charland, 2001: 137) rather than because the patient's reasoning flawed. Once again, this is seen as being problematic because competence assessments should focus on the patient's reasoning *process*, rather than whether her final decision outcome is regarded as a reasonable one. Specifically, the focus on the decision outcome rather than the decision process is antithetical to the doctrine of informed consent because competent patients: "...have the right to make 'unreasonable' choices" (Appelbaum, 2007: 1836).

However, an assessment of a patient's ability to reason need not focus on the reasonableness of her final decision, and can in fact focus on the reasoning process. Indeed, Freedman has addressed this concern by developing an account which he refers to as 'recognisable reasons.' According to Freedman, in order for a reason to be recognizable in terms of competence assessments then: "...it must contain both acceptable premises and a conclusion related to those premises...it is not required that the conclusion 'follow' from the premises, in that we believe the premises are *strong* enough to justify the conclusion" (Freedman, 1981: 64). Thus according to Freedman the decision made by the patient does not need to be entailed by the reasons she offers, rather her reasons must provide a strong justification for the conclusion. For example:

A Jehovah's Witness, injured in an accident, comes to hospital bleeding profusely. Blood transfusions are necessary to save the patient's life. The Jehovah's Witness refuses transfusions...the condition is curable, but without treatment death

results...the patient's decision is consistent with a set of beliefs that are well known, whatever we may think about them (Cassell, 1977: 16)

In this instance, the medical practitioner might think that the Jehovah's Witness' refusal of the blood transfusion is unreasonable: it is a relatively minor procedure that can be performed with little risk. However, given that this patient's decision is consistent with her religious beliefs, Freedman would determine that her refusal of the blood transfusion is 'reasonably' drawn and thereby that the patient meets the requirements of the (c) capacity for reasoning with the information given to her.

Failures of reasoning - indicating incompetence to make a make a medical decision - will occur when a patient's decision is based on false premises or irrelevant reasons. Freedman provides examples of incompetent reasoning in the case of a patient refusing a breast biopsy because of a belief that the surgery will affect her reproductive ability (false premise), and of a patient refusing to have surgery because it is a Tuesday (irrelevant reason) (Freedman, 1981: 64). The capacity thus focuses on the reasoning used to reach a decision rather than whether or not the medical practitioner regards the actual decision made to be reasonable.

A controversial example of suspected incompetence on the basis of reasoning with a false premise has been presented by Erbay et. al. (2010) in the case of a Muslim refusing medical treatment:

The ambulance physician making the evaluation, suspects that the patient might be experiencing intra-abdominal bleeding. Because blood loss is suspected, the patient [x] must quickly be administered serum by venous access. The healthcare

team starts to make preparations for the administration of the serum. The patient, however...objects to the administration of the serum. The day this is taking place is within the Islamic holy month of Ramadan and the patient is fasting. The patient states that his fast will be broken and his religious practice disrupted in the event that the serum is administered. The ambulance staff member informs him that his condition is life-threatening and that the serum must be administered. The patient now takes a more vehement stand. 'If I am to die, I want to die while I am fasting' (Erbay et. al., 2010: 652).

In this particular case it was decided that patient x was competent to refuse treatment. However, the claim that the administration of the serum is prohibited by Islam during Ramadan was misinterpreted by x. In fact, the saving of life is a central ethical principle of Islam. Furthermore, in cases of absolute necessity Islamic laws permit sacred acts such as fasting to be suspended (Gatrad and Sheikh 2001: 75) Indeed: "...the mufti encourages the doctor to force the patient to stop fasting if his medical condition so requires" (Rispler-Chaim, 1989: 205). In this case, x made his decision on the basis of the false premise that his religious practice prohibited the administration of the serum.

Erbay et. al do not regard the patient's mistaken belief in the rules of his religion to undermine his competence (Erbay et. al., 2010: 653). However, if a failure of reasoning due to the acceptance of a false premise is to be a measure of competence then this patient is incompetent to refuse medical treatment..

To be sure, it may be contended that even if the individual is mistaken about the laws of a religious doctrine, he at least has epistemic access to his own *interpretation* of the religion's demands. Thus, even though his decision is mistaken with regard to the religion he values, the decision he makes is compatible with his idiosyncratic interpretation of his religion. The patient's reasoning could therefore be determined as

competent on the basis that his reasons are based on his private religious values, even if they are mistaken with regard to general Islamic practice. Nonetheless, it is reasonable to suppose that were *x* to be made aware that his religious values are not shared by Islam, that he would make a different decision. For this reason it is reasonable to suppose that patient *x* makes his decision on the basis of a false premise and so lacks the capacity for reasoning, thereby undermining his competence. As this case highlights, determining whether the reasons used in the process of medical decision making are true or false can be a complicated task.

Recently it has been argued that the MacCAT-T test over emphasises the patient's ability to reason and that the test should also include reference to the patient's values: "...the individual must have a set of values or conception of the good that is at least minimally consistent, stable, and affirmed as his or her own" (Buchanan and Brock, 1989: 25). Buchanan and Brock claim that this further capacity is needed in order for the patient to reach a non-ambivalent decision; if the patient does not have a set of goals or a stable set of values then she will be unable to reach a decision outcome. For example: "...a depressed patient subject to frequent mood changes may repeatedly consent to electroconvulsive treatment, but then change his or her mind before treatment can be carried out" (Buchanan and Brock, 1989: 25). In this case the depressed patient's valuation of how well her life is going may change depending on her mood. Consequently, her refusal or consent to electroconvulsive treatment may vary in accordance with how she is feeling at a particular time. Supposedly, Buchanan and Brock would regard such a patient as incompetent to make a medical decision regarding whether or not she has electroconvulsive treatment because the value she places on her

mental health fluctuates over time. Thus (although they recognise that values do change over time) Buchanan and Brock claim that a sufficiently consistent set of values are: “...needed to permit, at the very least, a decision that can be stated and adhered to over the course of its discussion, initiation, and implementation” (Buchanan and Brock, 1989: 25).

However, it has been contested that the mere presence of a stable set of values is not an adequate measure of patient capacity. Primarily, Buchanan and Brock’s discussion of value fails to account for the existence of ‘pathological’ values. Specifically, it has been argued that patients suffering from anorexia nervosa are able to pass the MacCAT-T because, in a study by Tan et. al, they were generally found to have: “...a good understanding of the facts of their illness, its consequences, and the treatment...offered (Tan et. al, 2003: 701). Furthermore, these anorexic patients were also found to have a stable value system, valuing their thinness over and above anything else – including the continuation of their lives. The value systems of anorexic patients are thought of as pathological since their valuation of thinness is grossly disproportionate with the non-anorexic’s valuation of it:

Both the behaviour and subjective reports of people with a diagnosis of anorexia nervosa suggest that in many cases, the goal of thinness is valued more than their relationships with others, their health and even their own life (Craigie, 2011: 327).

It might be contested that a disagreement with or disapproval of an individual’s value system does not mean that that her value is pathological. Once again, recall that the purpose of informed consent is to enable patients from different religious and cultural

backgrounds to make medical decisions in line with their own value-systems. For instance, to take an earlier example, a medical practitioner may disagree with a Jehovah's Witness refusing a blood transfusion – but this does not mean that the patient is immediately incompetent to refuse the transfusion simply because the medical practitioner does not share her values.

However, Charland has argued that the value of thinness in chronic anorexia is pathological because it is directly caused by the disease:

In full-fledged chronic anorexia, the value of thinness acquires a different character. It also becomes a medical abnormality that is both caused and reinforced by the disease. Significantly, this medical abnormality in valuation varies with the incidence and severity of the disease (Charland, 2007: 284)

A further reason to suppose that the value of thinness is pathological for the anorexic patient is taken from case studies in which anorexic patients, who have passed the MacCAT-T test for competence, desire to be treated against their consent. For example, in the study by Tan et. al. (2003), one anorexic individual stated that she felt that she needed coercion in order to change her behaviour:

And I've needed threats, really, like you know, like if I start losing weight I will be admitted, because that's really scared me, and I need it to keep me going. Because it's not always enough to just want to do it...A lot of the time I just think they're not really serious when they say that [there is risk of physical harm and death], that it won't happen, then I just think, well, I don't have to do it [comply with treatment], then I feel guilty because I'm not being forced to do it (Tan et. al, 2003: 703)

In this case the anorexic patient wanted to be treated against her decision. This is even though she was found competent to refuse treatment on the MacCAT-T test for competence. Although under the Mental Health Act (2005) involuntary treatment in such circumstances is legal without reference to the patient's competence, allowing that: "...competent treatment decisions may be overridden in the context of a mental disorder" (Craigie, 2011: 327), the fact that anorexic patients can pass competence assessments despite rejecting their pathological value system suggests that the supplementary condition for competence posited by Buchanan and Brock is problematic.

Although each of the capacities required for competence on the MacCAT-T test for competence (bar (a) the ability to communicate a decision) and Buchanan and Brock's supplementary condition that the competent patient has a consistent set of values are problematic, they are nonetheless currently used to assess patient competence in medical practice. In the following discussion of competence it will be assumed that the competent patient is able to (a) understand information, (b) appreciate that information, (c) reason with the information, (d) express a choice and that she has a (e) consistent set of values, whilst the incompetent patient lacks all or some of these capacities. Although I have noted that the measuring of these capacities can be problematic, reliance on these capacities helps to roughly characterise the distinction between competent and incompetent patients referred to in the remainder of this chapter.

## **2.2 REBUTTABLE GLOBAL COMPETENCE**

British medical law adopts a rebuttable global standard of competence. Whilst non-rebuttable global standards of competence class an individual as competent to make all medical decisions regardless of the specific nature of the medical decision in question, the rebuttable standard presumes adults to be competent unless the converse is proven (Pollack and Billick, 1999: 304). An adult is thus: "...presumed to be competent or to have the mental capacity to enter into a particular transaction, until the contrary is proved" (English et al, 2004: 28). Thus, on the current legal standard, a patient that is presumed to be competent but suspected of incompetence will have her competence assessed by a medical practitioner; if incompetence is confirmed then the medical decision will be made on her behalf by a proxy.<sup>13</sup>

As I will show below there are two main motivations for adopting a rebuttable global standard of competence. It is, in the first place, practical to presume the competence of patients since to test for competence in every instance of medical decision making is both time-consuming and unreasonable. Secondly, competence is rightly thought of as task-specific; this means that whilst patients can be competent to make some decisions, the same patient will be incompetent to make medical decisions in other situations.

The rebuttable global standard of competence is practically beneficial since it avoids testing for competence every time a medical decision needs to be made. To test for competence prior to making any medical decision would be time-consuming given the

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<sup>13</sup> A proxy, or surrogate, is an authority appointed to make medical decisions on behalf of the patient; this may include the patient's guardian, medical practitioner or a court of law (Appelbaum et. al., 1987: 82).

volume of patients<sup>14</sup> and the number of decisions that may be required for the treatment of a particular ailment. Consider the impracticalities of repeatedly testing for competence in other areas of life - such as requiring driving tests every time a motorist uses her car, or demanding that dentists complete and pass examinations prior to every filling they give to a patient. The time consuming nature of testing for competence in every situation is of particular significance in the context of medical decision making since it risks the patient's health by delaying treatment. Indeed:

The commitment of professional time in an effort required to perform such assessments would be enormous at best, impossible at worst; and those resources would be much better spent in diagnostic and treatment efforts (White, 1994: 4).

It may be objected that the impracticality of repeated competence assessments is an insufficient motivation for presuming global competence; there is no reason to assume that ensuring patient competence will be easy. However, it remains reasonable to presume global competence given that most adults lead successful lives outside of the medical arena. Indeed, adult patients are likely to come from a background in which they have been educated, have jobs, interact with family and friends, and have an array of hobbies and interests which they successfully manage. With this consideration in mind, most adults will enter the medical arena with a degree of cognitive capability. It is thereby presumed that: "...anyone who possesses these qualities in everyday life is competent to give or withhold consent in a medical setting" (White, 1994: 48). The impracticality of testing for the patient's competence before she makes every medical

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<sup>14</sup> 16,806,200 patients were admitted to NHS hospitals in the UK in 2009/10 (NHS: The Information Centre, 2012)

decision is thus bolstered by the fact that adult patients are likely to already lead lives which they are competent to organise.

The second motivation for adopting a rebuttable standard of global competence is that competence is task-specific. Certainly, in other areas of life classifications of competence are made in relation to specific capacities required for a task. For example, a trained dentist will be competent to perform dental work but is likely to be incompetent to perform brain surgery, and likewise a qualified brain surgeon will probably not be competent to perform dental surgery. Competence should therefore be understood as: “...competence *for some task* – competence *to do something*” (Buchanan and Brock, 1989: 18) and vary with the individual’s ability to perform a particular task. Since an individual is only classed as competent if she is able to perform a certain task, she can be classed as incompetent when she is unable to perform a different task. For this reason: “[p]eople may be incompetent for one purpose yet be competent for others” (Winick, 1995: 24).

In the context of medical decision making a patient’s competence is rightly construed as being task-specific. Indeed, a patient’s competence may fluctuate in response to temporary factors. For instance, a patient’s decision making ability may be affected by: “...confusion, shock, fatigue, pain, or medication” (English et. al., 2004: 74). Take for example a case in which a patient is competent to consent to taking morphine for pain relief, but unable to consent to future medical procedures whilst under the influence of the drug due to a reduction in her ability to concentrate. Similar impairments to a patient’s competence will arise when there is an increase in the difficulty or complexity

of a particular decision that needs to be made.<sup>15</sup> For example, whilst a patient may be competent to consent to something simple like a blood test, she may be incompetent to refuse or consent to something more complicated like stroke surgery. Since she has difficulty understanding the risk factors involved in the procedure she thus may be found incompetent to refuse that particular treatment even though she is competent to consent to a blood transfusion. A patient's competence may thus vary in accordance with the specifics of the medical decision to be made. Whilst it is useful to adopt a global standard of competence for practical reasons, the rebuttable nature of the standard is motivated by the variability in patient competence with regard to particular decisions.

### ***2.3 REBUTTABLE GLOBAL INCOMPETENCE***

Whilst it is both practical and reasonable to adopt a rebuttable standard of global competence, it is widely agreed that global standards of incompetence are unacceptable. In medical practice, global standards of *incompetence* will class patients as incompetent to make *any* medical decision with all of their medical decisions being made by a proxy on her behalf (Appelbaum et. al., 1987: 82). Patients may be presumed to be incompetent for three main reasons:

- (1) Profound psychological disability: the permanently confused, profoundly intellectually disabled, or permanently comatose (White, 1994: 6).
- (2) Psychological impairment

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<sup>15</sup> See section 2.4 for an account of competence that varies with the riskiness of the decision made.

### (3) Being a minor<sup>16</sup>

A global standard of incompetence can be justified in (1) since such persons are categorically unable to recognise any medical decision that might need to be made. Cases in which a patient is permanently unconscious of the fact that a question of medical treatment has arisen, is “...unable either to make decisions or to make them with any degree of rationality” (Winick, 1995: 23). Testing for the competence of such patients for each medical decision that needs to be made would be futile since such patients are unable to make any medical decisions.

However, there are three grounds for dismissing the categorisation of global incompetence of patients in the latter two categories of (2) psychological impairment and (3) minors. These three grounds include:

1. The task-relativity of competence
2. Psychological damage
3. Developed competence

#### ***2.3.1 Task-relativity***

In order to determine the age and the level of psychological functioning below which patients are classed as globally incompetent a strict threshold must be drawn.<sup>17</sup> I will

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<sup>16</sup> In Britain young persons under the age of sixteen are classed as being generally unable to give informed consent (Mental Capacity Act 2005: Section 2.5)

firstly examine the case of mental illness and follow it with an example of age related incompetence in order to illustrate why an assumption of global incompetence in these cases is unacceptable. For example, in the case of mental illness we might class all persons with an IQ below 75 as incompetent to make any medical decision (Appelbaum et. al., 1987: 88). Those patients falling underneath the threshold will be deemed to be globally incompetent to make any medical decision, whilst those above will meet the rebuttable presumption of global competence.

The problem with fixing the threshold in this way is that there are likely to be incompetent and competent persons who fail to conform to it. For example:

...there are persons with IQs greater than 75 who may not be competent to make medical decisions in certain circumstances, such as an intoxicated auto accident victim [on the other hand] there are probably some people with IQs less than 75 who are capable of understanding the relevant information, at least about certain medical procedures that may be recommended for them (Appelbaum et. al., 1987: 88-9).

A fixed threshold of incompetence fails because it does not consider the task relativity of competence. Thus, when an individual is intoxicated, in shock or suffering anxiety, she may be incompetent to make a decision despite having an IQ over 75. Likewise, in the context of less complex medical decisions, a patient with an IQ under 75 may be competent to refuse or consent to treatment. For this reason, a global account of

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<sup>17</sup> Whether or not competence should be assessed in terms of a threshold is controversial. Instead it has been suggested that competence is always a matter of degree. Whilst a threshold assessment will draw a line (those patients falling under it being assessed as incompetent, and those on or above it as competent) a degree standard will measure competence on a continuum (White, 1994: 95-6). White has argued that threshold assessments are: "...artificial and practically impossible to implement" (White, 1994: 106) and so has argued that a degree standard of competence assessment should be adopted. However, since the threshold standard is adopted by the MacCAT-T test for competence (Grisso and Appelbaum, 1998:24-6) it will likewise be adopted here with the contentions surrounding the standard being left to one side.

incompetence fails to take into consideration the task-relative nature of medical decision making.

English case law supports the objection that classifications of global incompetence fail to take into account the task-relativity of competence. Both minors and the psychologically impaired have been judged as being competent to make medical decisions in certain circumstances. In *Re C* (1994) a paranoid schizophrenic patient was found competent to refuse an amputation after developing gangrene. With only a 15% chance of survival without the treatment, the hospital contended that C's competence to make this decision was impaired by his mental illness.

In this case, Dr. Eastman stated that C's schizophrenia gave him 'grandiose delusions' of having an international career in medicine. Dr. Eastman claimed that C's delusions prevented C from believing that the decision he was making applied to himself (*Re C*, 1994: 822). A second doctor also considered C incompetent to decide upon *all* medical matters because of his delusion that he was doctor, and a persecutory delusion that all treatment offered was calculated to destroy his body (*Re C*, 1994: 823).

However, in contradistinction to the medical doctors, the court judged that the patient had a sufficient degree of competence to make this decision:

Although C's general capacity to make a decision had been impaired by schizophrenia, the evidence failed to establish that he lacked sufficient understanding of the nature, purpose and effects of the proposed treatment, but instead showed that he had understood and retained the relevant treatment information, believed it and had arrived at a clear choice (*Re C*, 1994: 820).

As Thorpe, J. argued, the question of competence did not focus on C's chronic mental illness, but the extent to which his capacity was reduced by his chronic mental illness in this particular instance (Re C, 1994: 824). The court thus ruled that because C sufficiently understood the details of the proposed amputation he was competent to refuse the amputation in this circumstance, despite the underlying mental condition which the doctors believed rendered the patient incompetent (Re C, 1994: 824). The case importantly highlighted that patients suffering from mental illness may be occasionally capable of competent decision making.

Minors are usually treated as being globally incompetent to make medical decisions (Pollack and Billick, 1999: 304). This is partly based on a caveat of the Children Act (1989) which authorises the dismissal of a child's expressed wishes if her wishes are considered to go against her best interests (Dickenson and Jones, 1995: 289). Although the act stipulates that proxy decision making should be based upon: "...the ascertainable wishes and feelings of the child concerned" (1989, 3:a) it also asserts that the child's wishes should be balanced against her: "...physical, emotional and educational needs", and "...any harm which [she] has suffered or is at risk of suffering" (1989, 3:b, 3:e). For this reason a child's competence to refuse or consent to medical treatment is often dismissed by the courts if her decision is judged to be detrimental to her best interests.<sup>18</sup>

Once again classifications of global incompetence should be dismissed because of the task-specific nature of competence. Indeed, the variability of competence in minors is supported in the legal acknowledgement of 'Gillick Competence'. In the case of *Gillick v.*

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<sup>18</sup> The importance of constraining *competent* decision making in terms of protecting patient best interests is developed in chapter 9.

*West Norfolk and Wisbech Health Authority and Another (1986)* it was upheld that a child can sometimes be competent to consent to medical treatment. In the case *Victoria Gillick* instituted proceedings to appeal against DHSS family planning guidance that implied that in certain cases a doctor could lawfully prescribe contraception for a girl under 16 without parental consent. The majority decision of the court fell against *Victoria Gillick*, it being argued that in some circumstances a minor can be competent to consent to treatment, if she is capable of understanding what is proposed and is able to express her wishes (Gillick, 1985: 226) (i.e. in line with the criteria of competence features). Specifically, Lord Scarman proposed that: "...the parental right to determine whether or not a child under 16 would have medical treatment terminated if and when the child achieved a sufficient understanding and intelligence to enable him or her to understand fully what was proposed" (Gillick, 1985: 225). According to the *Gillick* decision, children are sometimes competent to consent to treatment depending on their level of understanding.<sup>19</sup>

The judgement of the *Gillick* case maps on to the definition of competence as the ability to perform a certain task in light of the context and circumstances of the decision, and for this reason it was the correct outcome. Indeed, neither minors nor mentally ill patients should be precluded from making decisions regarding their medical treatment by being treated as though they are globally incompetent; both minors and the psychologically impaired may be competent to make a medical decision if they meet the conditions of competence (outlined in section 2.1) for a particular decision.

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<sup>19</sup> More recently in 2008 the UK media highlighted the case of Hannah Jones, a 13yr old girl who was found to be *Gillick* competent to refuse a heart transplant (BBC, 2008)

### ***2.3.2 Psychological damage***

A further objection to classing both (2) the psychologically impaired and (3) minors as globally incompetent to make any medical decision is that it can precipitate: "...a decline in physical and psychological well-being" (Buchanan and Brock, 1986: 48). Bruce Winick has expounded in detail the psychological connection between incompetence 'labelling' and a decline in patient health, concluding that a classification of global incompetence can dramatically lower the patient's self-esteem, leading to depression and a decrease in motivation (Winick, 1995: 14-5).

Winick's claim that global incompetence 'labels' reduce patient motivation is supported in the judgments of *Re B* (2002). *Re B* involved a tetraplegic patient who requested the removal of artificial ventilation. In April 2001 the claimant was judged to be incompetent to make the decision to remove ventilation support and so her request was denied. An independent psychological assessment in July 2001 determined that the patient was in fact competent to make such a decision and the doctor who carried out the independent assessment: "...did not consider her to be suffering from depression and...considered her competent to make the decision to discontinue her treatment" (*Re B*, 2002: 454). Nonetheless, clinicians were not prepared to discontinue her ventilation support because B appeared to be ambivalent about her decision; despite her wish to cease ventilation she continued to accept rehabilitative treatment. For this reason the matter was brought to court - the patient maintaining that her ventilation treatment constituted unlawful trespass.

Importantly, Ms. B claimed in her statement that she expressed an interest in rehabilitation because: “[she] had not been assessed as having capacity” (Re B, 2002: 460). Ms. B viewed her decisions as subject to approval of a psychiatric competence assessment and did not want to follow through with her desire to have her ventilation removed in case she was judged to be incompetent. Furthermore, upon being judged to be competent Ms. B categorically rejected the option of rehabilitation. She claimed: “I had not changed my views, it is just that now I was assessed as being able to make a choice” (Re B, 2002: 460).

In this case, Ms. B had absolute confidence in her doctor’s assessment of her competence and so lost all motivation in pursuing her decision when she was judged to be incompetent. The initial judgement of incompetence thus had a detrimental effect on her motivation to seek the discontinuation of her treatment. This is unsurprising, since a decrease in motivation seems to follow naturally from classifications of incompetence; it would be odd to attempt to perform a task that you have been told you are incompetent to perform (Winick, 1995: 18). Judgements of incompetence may have a direct impact on whether a patient has confidence in her decision making abilities. We should be wary of classifications of global incompetence since they may diminish a patient’s motivation to attempt to make any decision at all – a decision which may in fact turn out to be competent.

Given the reduction in motivation caused by classifications of incompetence, Winick has additionally argued that classifications of global incompetence can be self-fulfilling. For both minors and the mentally ill an assumption of global incompetence will deprive

them of the opportunity to exercise their decision making skills. As a result, patients labelled as incompetent: "...may experience further loss of functional capacity" (Winick, 1995: 19). Indeed, in line with the capacities required for competence presented in 2.1, there are a variety of skills which must be developed for competent decision making, including a basic knowledge base, skills base, information processing, ability to concentrate, metacognitive skills and self-confidence (Dickenson and Jones, 1995: 293). Although these decision making capacities partially mature with age, it has been claimed that they develop most significantly with practice: "[h]ence, in court proceedings, greater emphasis should be given to the need for children to be allowed to make choices in order to develop this very capacity for mature decision making" (Dickenson and Jones, 1995: 98). Assumptions of general incompetence are thus not only unjustified with respect to minors and the mentally ill because they prompt a decline in motivation, in addition, determinations of global incompetence can be self-fulfilling by preventing patients from having the occasion to exercise and develop the capacities required for competent decision making.

### ***2.3.3 Fostering competence***

It has been claimed that a further issue with adopting global classifications of incompetence is that it contradicts the duty of care that a medical practitioner owes her patient.<sup>20</sup> Since competence can be affected by the circumstances and environment in which a decision is made, it is claimed that medical practitioners are obliged to facilitate competent decision making.

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<sup>20</sup> The duty of care is explained in chapter 1

Indeed, a patient who is thought to be generally incompetent due to some kind of cognitive impairment may be capable of making decisions: "...if a reasonable amount of time and energy are spent in the attempt" (Appelbaum et. al., 1987: 88). In terms of the capacities required for competence, any of those features might need aiding. A person with learning difficulties may struggle to understand the nature and consequences of a particular procedure. Another may find it difficult to make a reasoned decision and can be taken through the reasoning process to help them highlight flaws in reasoning. A person with depression may need counselling in order to ensure that she has the appropriate affective response to the decision to be made.

Thus, some patients who are presumed to be incompetent may in fact be competent to make certain medical decisions but need more help in reaching a decision. Consequently, because situations of decision making differ depending on the choice to be made and the environment in which it is made: "...competence cannot be an across-the-board affair" (Freedman, 1981, p57). Global accounts of incompetence cannot be justified because some patients need assistance in making competent decisions. Moreover, given that an assessment of incompetence can lead to a decline in psychological well-being, medical practitioners have a prima facie duty to foster competence in their patients under the duty of care.

As a result, although a rebuttable standard of global *competence* is both ethically and legally justified by an appeal to the ethical need to respect the patient's exercisable free choice and practical concerns within the medical arena, a presumption of global incompetence is only justified in limited circumstances. Excluding cases of profound

psychological disability, presumptions of global incompetence should be avoided for three reasons. Firstly, such presumptions have been shown to diminish the health of the patient creating a circumstance in which a designation of general incompetence is self-fulfilling. Furthermore, the treatment of both minors and the mentally ill as generally incompetent denies them the opportunity to exercise their free choice in situations in which they are competent to do so. It has also been argued that patients have a positive right to be aided in the development of their decision making capacities in order that they can make competent decisions. Leaving aside those who are profoundly psychologically disabled, no individual should be treated as globally incompetent to make medical decisions; instead competence should be assessed on a case-by-case basis.

#### ***2.4 VARIABLE STANDARDS OF COMPETENCE***

Given that global categorisations of incompetence are, in most cases, inappropriate, and the global standard of competence is rebuttable, a theoretical framework for determining when a patient is competent is required when it is suspected either that a globally competent patient is incompetent to make a particular medical decision or when it is suspected that a child or a psychologically impaired patient is capable of making a competent decision. In order to make distinctions between competent and incompetent decisions in light of the specific medical decision to be made this standard must be variable.

The variable standard of competence that will be considered here is the risk related standard. The standard posits that the threshold of competence varies in accordance

with the consequential risk of the decision made; since the risk posited is external to the decision process this variable account is classed as externalist.

A variable standard of competence has become popular because it claims to successfully achieve two key goals which can be outlined as follows:

- (1) Judgements of competence should be *task-specific*
- (2) Judgements of competence should focus on the *procedure* rather than the outcome of decision making

The first major factor offered in support of the adoption of a variable standard of competence is the perception that evaluations of competence are always task-specific, rather than global. As shown in section 2.3 competence is always relative to a specific task. If the risk related standard succeeds in addressing this feature then we have a good reason for supposing that it is a suitable account of measuring competence.

It is also claimed that an advantage of adopting a variable standard of competence is that it aims to determine the competence of a patient not in terms of the content of her decision but instead in view of the process by which the decision was reached. This can be seen as a reaction to the worry that outcome-based approaches could be abused by physicians who judge that the best or 'correct' decision conflicts with the: "...patient's own underlying and enduring aims and values" (Buchanan and Brock, 1989: 55-6). One motivation for assessing competence in view of the process of decision making rather than the content of the decision made is thus that determinations of competence which

are based on the content of a decision are subject to abuse by only recognising the patient to be competent if they comply with what the physician thinks is in the patient's best interests. Any decision which does not ultimately rest on the individual's informed preferences is: "subject to intolerable abuse in practice" (Buchanan and Brock, 1986: 33) and this is thought to be avoided by focusing on the process of decision making. An assessment of competence in terms of the content of a decision would 'pollute' "...the kind of competence an objective (and non-paternalistic) standard of competence aims to assess" (Cale, 1999: 132) and might confuse 'competence' with 'compliance.' If these concepts are confused a physician may: "...view *any* patient who disagrees on an important treatment decision as incompetent *just because of that disagreement*" (Wilks, 1997: 414).

Theorists are keen to avoid outcome-focussed standards of competence because it is claimed that a determination of competence based on the content of a decision will introduce the assessor's values into the assessment which may be unacceptable to the patient. This is viewed as being ethically unjustified in view of the nature of informed consent proceedings to protect a patient's exercisable free choice. Proponents of variable standards thus claim that an assessment of competence that successfully respects the patient's free choices will address the *process* of understanding and reasoning of the patient, *not the content* of his decision (Buchanan and Brock, 1989: 58). In fact, according to variable standards of competence, the competence assessment should be *indifferent* to the actual content of the decision made. By focusing on the process of reaching the decision, competence assessments are thus claimed to respect

the patient's free choices regarding her treatment as required by the doctrine of informed consent.

#### ***2.4.1 Risk related Standards of Competence***

Versions of the externalist risk related standard have been adopted by Drane (1985) and Buchanan and Brock (1989). In essence, this standard requires that the risk of the decision made - namely the resultant harm or benefit of the patient's choice and the probability of its occurrence - should determine the threshold for competence (Schermer, 2002: 37). The level of competence required to make a decision will 'track' the degree of risk of the decision so that "...a person has to be more competent to make decisions that carry substantial risk than those that carry minimal risk" (Buller, 2001: 102).

Furthermore, once the degree of competence required to make a decision of a particular risk has been determined, the ability of the patient to make this decision competently will be dependent on the functioning of a range of capacities. For example, a high or low threshold of competence will be ascertained depending upon the risk of decision involved. If it is determined that the decision is 'high-risk', a higher threshold of competence will be required, demanding a high functioning of the requisite capacities. Conversely, if the outcome of the decision is predicted to be low risk, a lower threshold of competence will require the minimal presence of these capacities. It is therefore claimed that the greater the risk of the decision, the greater need there is to ensure that "...the required capacities are actually present to the necessary degree" (Schermer,

2002: 37), whereas if the decision is thought to be of minimum risk and of little harm to the patient: “...then the decision making standard will be weak and a low level of understanding, reasoning skills, and the like will be required” (Wicclair, 1991: 94).

In section 2.1 I explained that there are five capacities used to assess patient competence (with only the first four being on the MacCAT-T test). These included the ability to (a) understand information, (b) appreciate that information, (c) reason with the information, (d) express a choice and that she has a (e) consistent set of values. On the risk related standard all of these capacities (a)-(e) will vary in accordance with the riskiness of the decision to be made. However Drane (a proponent of the risk related standard) makes reference to only two capacities required for assessing patient competence, including: (1) *Understanding*, and (2) *Rational decision making* (Drane, 1985: 17). According to Drane the significance of both the capacity for understanding and rational-decision making will vary, as a bundle, in accordance with the consequences of the particular medical decision made. As the consequences of the decision made become more serious, the: “...competency standards for valid consent or refusal of consent become more stringent” (Drane, 1985: 18), meaning that the level of understanding and rational decision making required will be higher. At the other end of the scale: “...the least stringent standard of competence to give a valid consent,” will require minimal understanding and rationality, and will apply to medical decisions that are not dangerous and are objectively in the patient’s best interests (Drane, 1985: 18).

Drane claims that both capacities of ‘understanding’ and ‘rational decision making’ can be varied according to risk. For decisions which are low-risk and beneficial only a very

basic functioning of capacities will be needed. This minimal standard will require an awareness of: "...orientation to one's medical situation" and an assent which is either: "...explicit or implied" (Drane, 1985: 19). Furthermore, low-risk decisions do not require a high level of functioning since: "[h]igher standards for capacity to give valid consent to this...type of medical intervention would be superfluous" (Drane, 1985: 18). Drane offers an example of when the low threshold of competence should be utilised. We are asked to imagine:

Betty Campbell, a twenty-five-year-old secretary who lives alone, has an accident. She arrives at the hospital showing signs of mild shock and suffering from the associated mental deficiencies; but her consent to blood transfusion, bone-setting, or even some minor surgery need not be questioned (Drane, 1985: 18).

According to Drane, even though Betty is suffering some mental impairment, she can be classed as competent to consent to treatment because she is aware that the treatment is required and implicitly consents to it. Conversely, for particularly harmful decisions the patient must attain a more demanding level of understanding and rationality. The patient must be able to *appreciate* what the decision involves and: "...the implications of the medical information for his or her life", requiring the highest level of understanding and reasoning (Drane, 1985: 20).

Thus, the greater the risk of the decision: "...the greater the level of communication, understanding and reasoning skills required for competence to make that decision" (Buchanan and Brock, 1989: 55). On the other hand, consent to a low-risk life-saving

procedure will require a minimal threshold for competence, meaning that in order to be classed as competent the patient must show a very basic level of understanding, reasoning and deliberation, and be able to communicate this consent in a basic way.

Significantly, both Drane and Buchanan and Brock's risk related standards are understood to be asymmetrical. Thus, although Betty is competent to consent to medical treatment - because the threshold in her case is extremely low - Betty would not automatically be competent to refuse the same medical treatment because the risks associated with refusal are very high. Consenting to a low-risk life-saving procedure which requires a minimal threshold for competence would thus require the highest level of competence from the *same* individual if that treatment were to be refused. For this reason, the risk related standard of competence allows that one individual can be classed as either competent or incompetent for the same procedure, depending on whether they refuse or consent to it.

#### ***2.4.2 The Inadequacy of the Risk related Standard***

As outlined above, variable standards of competence claim to achieve three key goals - namely that they are task-specific and process-centred. I will thus evaluate the variable risk related standards of Drane (1985) and Buchanan and Brock (1986, 1989) in terms of whether they succeed in achieving each of these three aims.

In relation to the first goal, the risk related standard succeeds in being task specific. The threshold of competence is fixed in accordance with the particular risk a decision poses

for the particular individual concerned. The standard of competence will thus vary in accordance with the decision to be made and the individual making it rather than the general mental health of the patient as rejected in 2.3.

Nevertheless, the risk related standard remains objectionable on two other grounds, which I shall term:

1. The problem of asymmetry
2. The focus on outcome

Firstly, many critics are uneasy about the prospect of asymmetrical competence judgements for the reason that: "...the same patient can be classified as decisionally capable or decisionally incapable, depending on which choice she makes" (Wicclair, 1991: 103). These critics argue that competence assessments should be *symmetrical* so that if a person is found to be competent they can make either a decision to refuse or a decision to accept treatment. A principle of symmetry thus requires that if a patient is competent to consent to a particular treatment in specific circumstances, then she also must be competent: "...to refuse the very same treatment in these same circumstances" (Culver and Gert, 1990: 620).

Wilks has attempted to defend the asymmetry of risk related standards of competence by appealing to our intuitions in situations analogous to medical decision making. By using an example of a tightrope walker Wilks claims that cases of asymmetrical competence are commonplace and that this makes it easier to accept in the medical

domain (Wilks, 1997: 424). Wilks asks us to consider the difference between: “...performing a high wire act with safety net in place below, and performing the *same* high wire act with net removed” (Wilks, 1997: 419), without the presence or absence of the net being communicated to the tight-rope walker. Someone with little talent who is likely to fall will *not* be competent to perform when the net is absent, but will be: “...perfectly competent to perform when it is in place” (Wilks, 1997: 420). This, according to Wilks, reflects an instance of acceptable asymmetrical competence. The *same* individual is classed as competent or incompetent to perform the *same* task depending on varying external factors, and this is justified because poor performance without the net is far riskier than walking with the net in place. Although we agree that the skills required for someone to traverse the wire successfully are the same in either case there is a difference: “...in something extrinsic to the person, in the level of risk the situation involves” (Wilks, 1997: 420). The tight-rope walker will thus be competent to walk with the net, but not without it, even though nothing about the tight rope walker changes. If we share Wilks’ intuitions in this case then we are supposed to concur that because cases of asymmetrical competence are intuitively acceptable then there is nothing unusual about adopting an asymmetrical threshold for competence in the medical domain.

There are two main reasons to dismiss Wilks’ example of the high wire act. Firstly, Wilks’ example conflates two different understandings of the term ‘competent.’ Rather than assessing whether the tight-rope walker is competent to traverse the wire or not, Wilks in fact assesses whether or not it is safe for the artist to walk the wire. As Cale rightly points out Wilks confuses the task of determining whether a person is competent

to make a decision, with making an incompetent, i.e. 'unsafe' decision. Wilks introduces the issue of safety into his example by failing to recognise: "...a real difference between making an incompetent decision, and being incompetent to make a decision" (Cale, 1999: 139). Since the probability that the person falls is equal "...the ill-performance of the tight-rope walker stays the same whether or not there is a safety net in place" (Cale, 1999: 141), it is not clear why the competence judgement should change. Instead of assessing the tight-rope walker's competence, all Wilks illustrates is that the tightrope walker is more or less likely to stay alive under varying conditions of risk.

Leaving aside Wilks' conflation of competent decision making with safe decision making, the central problem with Wilks' example is that it does not translate into the medical setting. According to the doctrine of informed consent, a patient cannot be judged as competent or incompetent unless they are *informed* about the procedures they are to undertake (1.2.3). For this reason, the competence of Wilks' tightrope walker should be assessed in relation to the decision that she makes when informed that the net is present or absent in order for it to be analogous with the risk related standard in medical practice. If she is informed that the net will not be present her competence can be assessed in relation to her reasoning and understanding of the probable harmful consequences of performing the act. It is not straightforwardly obvious that she will be incompetent to decide to traverse the wire if the safety net is absent, if she had the requisite understanding and capacity for rational decision making.

However, even with the caveat that the tight-rope walker be fully informed, it still remains open for the proponent of the risk related standard to endorse asymmetry. On

the basis of Wilks' example a proponent could still demand that the tight-rope walker must achieve a higher standard of decision making capacity to be competent to walk the wire when she is informed that the net will be absent. Indeed, Buchanan and Brock freely sanction that: "...just because a patient is competent to consent to treatment it does *not* follow that the patient is competent to refuse it and vice versa" (Buchanan and Brock, 1989: 51-2). A person will simply need a higher level of understanding and rational decision making in order to refuse her treatment than to accept it. For example, if we return to the case of Betty, although she is competent to consent to treatment, she would not be immediately competent to refuse that same treatment because her mental deficiencies might render her unable to attain the high level of understanding and rational decision making required to make that refusal. Thus despite the fact that she can competently consent to treatment because she has minimal awareness and implicitly consents to it, minimal awareness and presumed consent are not sufficient to refuse that treatment on the risk related standard. A person can thus be competent to consent to a treatment, but not to refuse it. Asymmetry can thus be accepted as an inevitable by-product of a risk related standard, and the externalist can: "...unashamedly endorse this asymmetry and...see it as no problem at all" (Buller, 2001: 104).

Even though asymmetry can be accepted in principle, the risk related standard still faces the second objection that it is outcome rather than process oriented. Although proponents of the standard claim to focus on the process of the decision made by making the assessment of competence via capacities such as understanding and rational deliberation, it is not entirely clear what the capacities are supposed to involve and

whether they are independent of what a doctor considers as being in the patient's best medical interests.

Proponents of the risk related standard fail to base judgements of competence on features of the patient and instead base them on the decision the patient makes. Because the competence judgement is made on the basis of the decision rather than on features of the decision maker, then the externalist mistakenly thinks that there are two decisions to make, either a yes-decision, or a no-decision, rather than that there is only one decision which can be made either way (Buller, 2001: 105). Problematically, if a competent patient is only allowed to make one of two decisions it seems to be implausible to judge that a competent patient is freely choosing it since certainly, "...where there is only one option, there is no choice. Where there is no choice there is no decision and hence no need for decision making ability" (Maclean, 2000: 286). The focus on the consequences of the decision rather than on the patient's cognitive capacities to make the specific decision is thus not only problematic for adherents of the risk related standard as outcome standards are explicitly rejected by them, but because it also undermines the doctrine of informed consent's emphasis on respect for patient free choice.

The problem with the risk related standard is thus that it gives primacy to considerations of the duty of care over the aim of informed consent to respect the patient's exercisable free choice. Far from balancing the competing factors of free choice and best interests the risk related standard ignores free choice on both high and low thresholds and instead gives primacy to considerations of patient best interests. On the

lower threshold decision making standards are extremely basic so that as long as a patient is minimally aware of the procedure being offered and of their medical condition: "...they will be classified as decisionally capable, regardless of their mental status" (Wicclair, 1991: 99). This means that someone who that is mentally impaired will be classed as competent if they can communicate in a basic way that they assent to low-risk, life-saving treatment. Even Drane concedes that on his risk related account patients that are retarded, mildly senile, demented or even intoxicated can qualify as competent decision makers on the low-threshold (Drane, 1985: 19).<sup>21</sup>

Against Drane, the minimal capacities of awareness and assent which are required on the low threshold should not be characterised as conditions of competence. In fact, there is little we could call 'self-determination' on this lower threshold, as a patient would be considered competent to make a medical decision even though she has very little understanding (Schermer, 2002: 38). The adoption of what is considered to be a low-risk and acceptable decision therefore does not constitute respect for exercisable free choice of the person making it but is instead classed as a competent decision because it conforms to what is in the patient's best interests. Minimal awareness and *presumed* consent do not constitute autonomous decision making just because the decision corresponds with what is supposed to entail the least risk for the patient, for as Wicclair appropriately points out, if a two year old child does not want to play in the street or pet a strange dog, it does not follow that the child is competent to decide whether to play in the street or to pet strange dogs (Wicclair, 1991: 99). The value of autonomy is thus

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<sup>21</sup> Importantly this is not because such patients are not *capable* of competent decision making – as argued in section 2.3 such groups of people can make competent decisions. The criticism here is raised against incompetently formed decisions being treated as competent because they are low risk and conform with the individual's best interests.

irrelevant on the low-threshold because a patient does not need to be autonomous in order for her decision to be accepted as competent.

It might be suggested that allowing incompetent patients to be classified as competent on the low-threshold is not problematic since whether or not the patient is determined to be competent the very same medical treatment will be given. For example, a schizophrenic patient may be found to be competent to consent to a blood transfusion despite reasoning that the process will rid him of impurities planted in his circulatory system by aliens, because the decision is low-risk and corresponds with his best interests. If the patient were to be found incompetent to consent to this treatment because of his delusions, he would still be given the blood-transfusion. Either way, classifications of competence and incompetence on the low threshold seem to make no difference to the treatment provided. It is thus suggested that the classification of the schizophrenic patient as competent is harmless since it does not effect any change in his medical treatment.<sup>22</sup>

However, there are strong reasons deny this claim; firstly a false classification of competence fails to respect the patient's free choice as required by the doctrine of informed consent, and secondly the basic capacities required for competence on the lower level risks leaving the patient uninformed. To take a separate example we might imagine a Jehovah's Witness suffering from amnesia and similarly in need of a blood transfusion. Since the procedure is low risk the patient need only implicitly consent to the treatment and be minimally aware of her circumstances. When she assents to the

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<sup>22</sup> I owe thanks to Dr. Nikk Effingham for raising this point.

transfusion she is subsequently judged to be competent to do so. However, the competence assessment in this example clearly fails to respect her exercisable free choice since her decision conflicts with her underlying religious belief which prohibits blood transfusions. Classing patients as competent on the low-threshold, which requires the bare minimum in decision making capacities, is wrong because it disrespects the patient's right to make free choices as required by the doctrine of informed consent.

Moreover, classing a patient as competent because they are minimally aware and implicitly assent to treatment risks classifying her as competent because she complies, despite the fact that she has not been fully informed about the procedure. Tom Shakespeare has proposed that this is already the case in ante-natal genetic testing: "[t]here is evidence that the choice to have ante-natal tests, and the freedom to decide whether or not to proceed with pregnancy, is not as free and open as the medical establishment would suggest" (Shakespeare, 1998: 675). Shakespeare claims that because obstetric procedures have become routine, testing often takes place without the patient's knowledge, let alone her consent (Shakespeare, 1998: 675). It is likely that in these cases of low risk diagnosis the patient is presumed to consent to the treatment because it is judged to correspond with her, and the future child's, best interests. Certainly, as has already been shown, on the low threshold presumed consent is sufficient for being judged a competent decision maker. However, as Shakespeare correctly notes: "If the notion of choice and informed consent in ante-natal screening is to be a reality, parents have to be trusted to make their own decisions about their pregnancies" (Shakespeare, 1998: 678). Thus, in order for the doctrine of informed consent to be properly respected the competence assessment must not only judge

whether the patient's decision is autonomous but must also be based on the requirement that the patient is fully informed. Since the risk related standard allows that a patient can be classed as competent even though her decision was not free - or indeed that the patient she was not even minimally informed of the treatment - the risk related standard fails to respect the patient's right to self-determination on the low-threshold of competence assessment.

There is also a danger on the risk related standard that the capacities required for competence, such as understanding and reasoning: "...will be set arbitrarily and unattainably high by those who believe that paternalism is justified when perceived risks are great" (Wicclair, 1991: 99). Maclean refers to this as a form of 'dishonest paternalism' because instead of overriding a patient's competently made decision in the interest of protecting their best interests, on the risk related standard: "...whenever it really matters, we simply raise the standard required and say that the patient is not competent to make the decision" (Maclean, 2000: 282). Thus, although proponents of the risk related standard claim that competent patients are never overruled, this is in fact a fiction: "...the reality is that they are calling any patient incompetent who makes a decision they believe it is justified to overrule" (Culver and Gert, 1990: 638).<sup>23</sup> Despite its claims to the contrary, the risk related standard fails to balance autonomy with considerations of well-being on both the higher and lower thresholds. In fact autonomy is distinctly out-weighted by considerations of the patient's best interests on low and high thresholds of the risk related standard.

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<sup>23</sup> This does not mean that a risk related standard is logically impossible, rather that it is practically open to abuse. I leave it open as to whether an 'ideal' risk related standard can be developed.

Risk related standards of competence attempt to offer a variable account for determining the threshold of patient competence, the requirements for achieving competence varying according to the potential risks and benefits of the decision made. It has been adopted because it is thought to incorporate three desirable goals, specifically, that it is task-specific and process-centred. However, I have shown that out of the three goals it purports to embrace, the risk related standard only succeeds in being task-specific. I have shown that although the common objection that the risk related standard is asymmetrical can be dismissed, the standard remains objectionable on the grounds that it is outcome focussed and thereby does not respect patient free choice as required by the doctrine of informed consent.

I have argued that the risk related standard does not respect patient autonomy in terms of respecting patient free choice; on the lower threshold of decision making the required functioning of capacities are extremely basic so that almost anyone could be classed as a competent decision maker. Persons we would normally regard as being incompetent, and lacking medical decision making ability, would thus be classed as competent to make low-risk medical decisions. Similarly, on the higher threshold for competence what is prima facie a focus on the ability of the patient to formulate an autonomous decision via the capacities of understanding and rational decision making can in fact be reduced to the outcome of the patient's decision since the threshold can continue to be raised until the patient's decision coincides with what the medical practitioner considers to be in the patient's medical best interests. Since the risk related standard fails to respect patient free choice on both lower and higher thresholds it is therefore an unsuitable guide for measuring patient competence the proponent of informed consent

procedures to adopt. Consequently, the problem of determining patient competence indirectly supports the reversal of the prioritisation of informed consent above considerations of patient best-interests, thereby motivating the adoption of hard paternalism as defended in chapter 9.

## ***2.5 MAKING MEDICAL DECISIONS FOR INCOMPETENT PATIENTS***

As noted in section 1.1.2 the doctrine of informed consent only requires that the decisions of competent patients are respected. For incompetent patients a distinctive medical decision making technique must be used. A method used for making decisions on behalf of patients that make incompetent decisions is the substituted judgement standard (SJS). In the following I present two problems with SJS firstly that the judgement the incompetent person would have made is epistemically opaque and secondly because the internal and external conditions of the imagined competent patient cannot be determined: the large number of possible conditions lead to a multitude of possible decision outcomes. Finally I hint that the central difficulty with SJS is that it assumes that ethical medical decision making is served by respecting free choice (in this case the free choice that the patient would have made were she to be competent). As I will show in Chapters 6 and 7, this assumption cannot be sustained.

### ***2.5.1 The Substituted Judgement Standard (SJS)***

On SJS the proxy decision maker attempts to make a medical decision for the patient on the basis of the patient's likely preferences. It is claimed that: "...a patient's religious

values or philosophical preferences can be determinative of post-competence care” (Cantor, 2005: 103). Support for this standard has been derived from common law and constitutional rights to self-determination and privacy (Dresser and Robertson, 1989: 234). It is argued that in order to respect incompetent patients they should be accorded the same right to refuse treatment accorded to competent patients, leading the courts to appoint a surrogate : “...to choose as they think the patients would have chosen when or if competent” (Dresser and Robertson, 1989: 235).

SJS can be most precisely formulated as a counterfactual. Consider a case in which a designated surrogate decision maker (x) consents to the termination of incompetent patient (y)’s respirator. The counterfactual definition of SJS denotes that a surrogate (x) decision is a valid decision on the incompetent patient’s (y) behalf iff:

(i) x is a legally recognised surrogate for y and (ii) in the nearest possible world to the actual world in which y is able to offer consent, y consents to the termination of the respirator in the actual world (Nagasawa, 2007: 20)

The advantage of this definition is that it allows us to imagine what the incompetent patient would choose without requiring that she miraculously becomes competent in the actual world. Furthermore, the definition allows the incompetent patient’s competent counterpart to apply judgement to the actual world of the incompetent patient. We thus avoid any difficulty of the competent counterpart making incongruent decisions in a world in which she is in fact competent. I subsequently rely upon this definition below, in order to reject SJS as a method of making medical decisions for formerly competent patients.

### **2.5.2 Formerly Competent Patients**

A case in which SJS has been used is in the case of patients who were once competent but through deterioration in health have become incompetent to make decisions about their medical treatment.<sup>24</sup> The landmark case of Karen Quinlan exemplifies an instantiation of making a medical decision for a formerly competent patient on the basis of SJS. In this case, the formerly competent Karen Quinlan suffered a cessation of breathing (for unclear reasons) leading to permanent brain-damage which left her in a persistent vegetative state with no reasonable hope of recovery (Re Quinlan, 1976: 7). The court asserted that Karen still had an “independent right of choice” despite lacking the competency to assert it. They concluded that her:

...right of privacy may be asserted on her behalf by her guardian under the peculiar circumstances here present. If a putative decision by Karen to permit this non-cognitive vegetative existence to terminate by natural forces is regarded a valuable incident of her right of privacy, as we believe it to be, then it should not be discarded solely on the basis that her condition prevents her from conscious exercise of her choice. The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to [decide] as to whether she would exercise it in these circumstances” (Re Quinlan, 1976: 24-5).

In this case it was argued that an incompetent patient has a right to determine her medical treatment. However, since she is incapable of asserting this right, due to her incompetence it must be asserted on her behalf by a surrogate in light of what they think the incompetent patient would have chosen.

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<sup>24</sup> Notably, SJS is an inappropriate standard for making medical decisions for the never competent patient. The biggest difficulty is that such patients do not have any previous values or preferences to draw upon when making a medical decision on their behalf. Indeed, a never-competent patient will not have previous clearly expressed preferences, let alone values. (Note, that this does not mean that the never-competent patient does not have preferences. The problem is rather that these possible preferences are inaccessible to the surrogate decision). In order to make decisions on behalf of never competent patients a standard of best interests must be applied. For a developed account of best interests see Chapter 7 and for its application in medical decision making see Chapter 9.

However, as a method of making medical decisions for the formerly competent SJS has been successfully criticised on two grounds. Firstly the standard is recognised to be impossible to apply because the would-be competent patient's decision is epistemologically opaque. Secondly, SJS cannot be safely employed because the content of the standard is undetermined; this leads to the problematic implication that many different decision outcomes are compatible with the standard.

To begin with: "...the major problem commonly thought to plague this standard is, directly or indirectly, *epistemic*" (Broström et. al., 2007: 266). The difficulty is that there appears to be no way of determining whether the surrogate's decision is valid because although the surrogate can make a reasonable guess at the incompetent patient's wishes, there is no way of definitively knowing what the hypothetically competent patient would have chosen. According to the counterfactual definition of SJS we can determine the validity of a surrogate decision by identifying the decision made by the competent patient in the closest possible world. However, this identification is both epistemologically and metaphysically impossible, since: "...there could be two or more possible worlds that are the closest possible worlds to the actual world in a relevant context" (Nagasawa, 2007: 22). Thus, it might be the case that in one of the two closest possible worlds the patient consents to treatment, but in the other refuses treatment. Since it is: "[o]nly in cases in which this counterfactual is true [that] the decisions of surrogates based on the counterfactual wishes ascribed to patients [are] valid" (Barnbaum, 1999: 169), the epistemological barrier to knowing what the incompetent patient would choose is a serious problem for the standard.

The second problem for SJS is that the internal and external decision making conditions of the incompetent patient's competent counterpart are undetermined. According to Broström et. al. (2007), in order for SJS to be justified we need an account of hypothetical decision conditions in order to work out which counterfactual version of the competent patient's decision validates the surrogate's decision. Indeed, until more is described in terms of the counterfactual situation: "...there is simply no answer to the question of what the patient's decision would be" (Broström et. al, 2007: 268).

Broström et. al offer several different ways in which a proponent of SJS could determine the nature of the counterfactually competent patient and her environment. These include, the last decision conditions of the patient before she became incompetent (Broström et. al. 2007: 270); past decision conditions of the patient when she was more competent to protect her interests (Broström et. al. 2007: 271); peak decision making conditions: "...the ones holding when [the patient] had the best chances to make a clearly autonomous decision promoting [her] own interests" (Broström et. al. 2007: 272), characteristic decision conditions – the sort of decision the competent patient is likely to make given characteristic traits featuring the patient's life as a whole (Broström et. al. 2007: 273); a mixture of all the above decision making conditions (Broström et. al. 2007: 274); or idealised decision making conditions: "...to disregard, or compensate for, whatever bad luck [the patient] may have had in [her] life, which has forced [her] to make decisions under conditions that are not fair to [her] potential" (Broström et. al. 2007: 275). In order for SJS to be accurately applied we need both the internal and external criteria for determining which version of the patient's counterfactually competent self we want the surrogate's decision to correspond to, since: "...our choice of

decision conditions could make a difference to the outcome” (Broström et. al. 2007: 275). Since there are a variety of ways in which the criteria could be determined which could possibly result in different decision outcomes SJS is an unsuitable method of ensuring that the formerly competent patient’s free choice is respected.

A more comprehensive concern regarding SJS is that it assumes that refusal of or consent to medical treatment makes that decision outcome ethical so long as it was freely chosen – since SJS attempts to figure out what the formerly patient would have chosen were she to be competent, it assumes that the most important factor in determining the medical treatment to be pursued is the one that the patient would have wanted. As I will show in Chapters 6 and 7 this assumption regarding the importance of free choice cannot be sustained either in the role of competent medical decision or in terms of making medical decisions on behalf of formerly competent patients.

## ***2.6 CONCLUDING REMARKS***

Determining patient competence is important for the proponent of informed consent since only competent patients are recognised as being able to give or refuse consent. In this chapter I have outlined some of the main features of competence and the difficulties of determining whether a patient has them to a requisite degree. The capacities required for competent decision making include the ability to (a) understand information, (b) appreciate that information, (c) reason with the information, (d) express a choice and that she has a (e) consistent set of values (section 2.1). Although it was shown that determining whether these capacities were functioning in a patient is problematic, I

referred to the functioning of these capacities in order to draw a rough distinction between competent and incompetent patients.

In addition I argued that whilst a position of rebuttable global competence is protected in law (section 2.2) it is unacceptable to treat the psychologically impaired and children as globally incompetent (section 2.3). I also indicated that there are problems with adopting a risk related standard of competence in order to determine whether a patient has the requisite functioning capacities (section 2.4.1 and 2.4.2) and suggested that such difficulties provide an indirect case for adopting paternalism in medical decision-making. Finally I sketched some preliminary concerns with adopting the substituted judgement standard of decision making (SJS) when making medical decisions on behalf of formerly competent patients (section 2.5.1). I also noted that the central concern with SJS is its reliance on the assumption of informed consent that medical treatment decisions are ethically justified so long as the patient has freely chosen it. In order to explain why this assumption should be rejected I spend chapters 3-6 explaining the nature of free choice and provide argumentation as to why the ethics of medical treatment should not be governed by patient free choice, either explicitly in terms of informed consent and competent decision making, or in terms of SJS and decision making on behalf of incompetent patients.

## CHAPTER 3: THE NATURE OF FREE CHOICE

As shown in section 1.3.1 a common justification for informed consent procedures is the moral demand to respect individual autonomy understood as respect for free choice. There it was presented that under the doctrine of informed consent the demand to respect individual autonomy is equalled to a demand to respect patients' free choices. Furthermore, in section 1.4 I noted that when conflicts arise between the duty of care and the doctrine of informed consent the importance of informed consent is prioritised above the duty of care. From here on I shall refer to the unqualified prioritisation of informed consent over the duty of care as 'absolutism': this is the position that respect for competent patient choices is *always* more ethically important than upholding the duty of care. A full account of absolutism, will be developed in Chapter 5 and objected to in Chapter 6.

However, before it is possible to reject absolutism, and thereby the total prioritisation of informed consent procedures above ethical considerations as protected by the duty of care it is necessary to present an account of the nature of free choice. To this end in this chapter I develop my own analysis of 'exercisable free choice' (section 3.2), drawing upon concepts of de jure liberty (section 3.1.1), de facto liberty (section 3.1.2), the capacity for autonomy (section 3.1.5) and freedom of action (section 3.1.6).

### **3.1 CONCEPTUALISING FREEDOM OF CHOICE**

A key assumption of informed consent is that competent patient free choice is of value and must be protected (sections 1.2.3 and 1.3.1). However, in order to assess whether this assumption can be sustained it is necessary to determine what the concept of 'freedom' entails, since we need to know what it is that is to be protected before we can determine whether it is worth protecting. In this section I present definitions of six of the concepts commonly associated with the exercise of free choice:

3.1.1 De jure liberty

3.1.2 De facto liberty

3.1.3 Freedom

3.1.4 Autonomous persons and free choice

3.1.5 The Capacity for Autonomy

3.1.6 The relationship between freedom of action and freedom of choice

Determining what is meant by 'freedom of choice' is complicated by the fact that it has been associated with a variety of philosophical concepts, including liberty (3.1.1-3.1.2), freedom (3.1.3, 3.1.4 and 3.1.6) and autonomy (3.1.5). Before we can assess what is meant by 'freedom of choice' it is necessary to understand what the concept 'freedom' denotes. I argue that the *exercise* of free choice involves a complex relationship between these concepts.

Historically, the nature of freedom has been understood in terms of Isaiah Berlin's two concepts of liberty. Berlin defines negative liberty as the area of non-interference, meaning the absence of restrictions on individual action or choice:

If I am prevented by others from doing what I could otherwise do, I am to that degree unfree; and if this area is contracted by other men beyond a certain minimum, I can be described as being coerced, or, it may be, enslaved...Coercion implies the deliberate interference of other human beings within the area in which I could otherwise act (Berlin, 2006: 34).

In this passage, Berlin associates negative liberty with 'being prevented by others from doing what I could I otherwise do'. However, as it stands this is an incomplete definition. Indeed, we might wonder who the relevant 'others' are. Will this include the judiciary and/or other citizens? Furthermore, we might question whether the unintentional consequences of the others' actions count as restriction on freedom? We might also ask whether interference with individual *action* or *choice* constitutes an interference with negative liberty and what the areas are in which the individual could 'otherwise act'?<sup>25</sup> Answers to these questions will be explored below.

According to Berlin, positive liberty is defined as 'being one's own master', or the source of what one does: "I wish my life and decisions to depend on myself, not on external forces of whatever kind" (Berlin, 2006: 43). Here, again, we are left with questions as to what conditions are required for being capable of making one's own decisions, or whether *only* external forces impede the self-governance of one's life? Also, the definition of positive liberty leaves unanswered the question as to whether it is

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<sup>25</sup> It is worth pointing out that theorists have traditionally equated negative liberty with the absence of all constraints, judicial or circumstantial: "...all cases of negative liberty are at once cases in which I am free from constraint and in consequence free to act should I choose" (Skinner, 2006: 244).

important that one can act on one's choices, rather than just decide upon them. As presented, the definition of positive liberty as being 'one's own master' is incomplete and so fails to explain when an individual exercises freedom of choice.

Due to the uncertainty surrounding the nature of freedom my definition of the following concepts – whilst being partly stipulative - will in part draw on the categorisation of these terms made by Joel Feinberg (1986). The definitional imposition I make on the concepts associated with freedom will enable me to present a coherent picture of what is meant by 'freedom of choice'. I thus attempt to resolve the questions surrounding the nature of negative and positive liberty by providing a precise delineation of the concepts involved in the exercise of free choice.

### ***3.1.1 De jure Liberty***

The concept of de jure liberty will be used to denote *judicial* licence. An individual has de jure liberty to act and choose how to determine her life so long as her judicial authority rules that she is permitted to act in a certain way (Feinberg, 1986: 63). For example, an authority may rule that an individual has license to enter homosexual relationships. We may then say that persons under that jurisdiction have *de jure liberty* to act in this way.

Likewise an individual's de jure liberty will be restricted by judicial prohibitions. For instance, it may be judicially ruled that individuals are not permitted to drive without having an appropriate level of vision. Persons with impaired vision will lack the *de jure liberty* to drive cars, since it is prohibited by law. A person's liberty is thus partly

measured in terms of the governing laws in her jurisdiction; one has *de jure liberty* to perform certain actions and make certain choices so long as they are judicially permitted (Feinberg, 1986: 63).

Within the domain of De Jure liberty a distinction can be made between an individual's negative and positive rights. These rights place limits upon how far the legislature and its citizens can restrict an individual's freedom. The presence or absence of negative and positive rights will thus determine the area in which an individual is *entitled* to exercise her freedom.

Negative rights are entitlements to non-interference, legally drawing the boundaries in which an individual is free to act and determine her life without the interference of others. Freedom of choice can, in part, be treated as a negative right. Indeed, negative rights are commonly associated with: "...the right of individuals to make their own decisions without interference from others" (Katz, 2002: 105). This right is negative since it entails: "...someone else's duty to *abstain* from interference with one's intended course in life" (Faden and Beauchamp, 1986: 7 [my emphasis]). Note that negative rights to freedom of action and choice do not correspond to de facto liberty, since they are protected in legislation.

The negative rights to freedom of action and choice will interfere with the de jure liberty of others. Not only does the right to freedom of choice permit the individual to act without interference from others, but it will also limit the behaviour of others so that they cannot legally interfere with the free choices and actions of others. To have the

negative right to freedom of choice involves limiting the behaviour of others by legally preventing interference with the freedom of other individuals.

The protection of the negative right to freedom is guaranteed in the right to privacy as expressed in Article 8 of the European Convention on Human Rights and Fundamental Freedoms: “1. Everyone has the right to respect for his private and family life, his home and his correspondence” (1953, 8.1). Restrictions on this right include other laws, national security, public safety, economic well-being, prevention of disorder or crime, the protection of health or morals, or the protection of the rights and freedoms of others (1953, 8.2). The scope in which an individual has the negative right to non-interference in her free choices is inclusive of all areas not included in the restrictions outlined above.

Positive rights entitle individuals to the provision of a good or a benefit. Although the right to freedom of choice and action are less obviously positive rights, positive rights are essential for allowing the individual to exercise her freedom of choice in a *meaningful way*<sup>26</sup>; having the negative rights to freedom of choice is moot if one cannot exercise one’s freedom in the way one wants to. Indeed, although a woman might have the negative right to identify her gender as male, she will not be able to biologically live as a man if no one is willing to perform transgender surgery on her. The protection of freedom thus: “...implies both negative rights (e.g. the right not to have surgery imposed on oneself against one’s will) and positive rights (e.g. the right to have surgery performed on oneself if one voluntarily chooses – and the surgeon is willing)” (Feinberg

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<sup>26</sup> Recall the similar point raised against the classification of global incompetence in section 2.3.3., there it was argued that medical practitioners have a duty to foster the capacities for competence in their patients. This is also an instance in which a patient could be thought of as having a positive right.

1986: 53). Rights to freedom, whilst naturally falling within the remit of negative rights could also be recognised as positive rights to have opportunities provided for individuals with which they can exercise their freedom.

### ***3.1.2 De Facto Liberty***

De facto liberty encompasses the area not covered by judicial restrictions or permissions. A person has de facto liberty to the extent that she is not legally permitted or banned from performing certain actions or making certain choices. For example, consider the absence of a law governing the kind of food individuals may eat. Since there is no legal restriction on the type of food an individual can eat she exercises her de facto liberty when she chooses her meals.

Note that the scope of de facto liberty is dependent upon the absence of laws permitting action. The absence of a law governing what individuals may eat only constitutes de facto liberty if there is no corresponding law *permitting* individuals to eat the food of their choice. Indeed, if there were such a legal permission then choice of food would fall within the domain of de jure liberty. Thus, it is the absence of either legal restrictions *or* legal permissions that constitute the scope of an individual's de facto liberty.

### ***3.1.3 Freedom***

An individual's freedom is not constrained or advanced by the presence or absence of judicial restrictions, but rather by circumstantial factors or the intentional restrictions made by others. In this conceptualisation, one's freedom is only restricted when

circumstances other than enforced laws prevent us from doing what we are free to do (Feinberg, 1986: 63). A person may thus be free to act in judicially forbidden ways.

It should also be noted that a person's freedom can be broadened by circumstantial factors. For example, a person with impaired vision is still *free* to drive her car - even though she is not at liberty to do so - because although her judicial authority has classed it as illegal it just so happens that there are no non-judicial external factors preventing her from getting into her car and driving away. Alternatively, a person's freedom can be restricted if there are circumstantial hindrances to her action. Indeed, the individual with impaired vision will be unfree to drive her car if she is locked in a cell or lacks a key to start the engine of her car. In this case she is thus both unfree and not at liberty to drive her car in terms of de jure liberty.

It has been proposed that scope of freedom can only be measured in terms of the absence of *intentional* constraints made by another person. Jones and Sugden argue that: "[a] person is unfree to the extent that he is prevented from doing something by the actions or plans of another person" (Jones and Sugden, 1982: 51). Steiner similarly proposes that: "[a]n individual is unfree if, and only if, his doing of any action is rendered impossible by the action of another individual" (Steiner, 2006: 123). For example, imagine an individual wants to watch a particular sports match on the television, which her partner finds uninteresting and boring. When her partner hides the remote control for the television, her freedom to watch the programme is restricted by his intentional action. She is thus unfree to watch the match. Such theorists thus propose that freedom is only constrained by the interference of other persons.

Although this analysis of freedom is partially correct, it is reasonable to suppose that restrictions on freedom include more than the intentional interference of other persons. Indeed, unintentional consequences of another's actions can also restrict an individual's freedom. Hirschmann (2006) correctly argues that non-intentional impediments to my options can restrict freedom. For instance, an unintended distribution of wealth within a society could lead to instances of poverty severely restricting the freedom of the least well-off (e.g. they cannot afford to take holidays, or afford specialist medical treatment from private clinics). The restrictive conditions of poverty would cause a significant reduction in freedom if the situation could be avoided or remedied by human action, even though the consequences of wealth distribution are unintentional (Hirschmann, 2006: 212). A person's freedom can thus be reduced by unintentional consequences of others persons' actions. Freedom can thus be defined as the absence of non-judicial constraint. An individual is not unfree because of the judicial constraints on her action, but because of circumstantial factors preventing her action or choice.

Within the concept of freedom a distinction can be made between freedom of action and freedom of choice. Whilst certain circumstantial factors will prevent an individual from *acting* freely, other sorts of factors will prevent an individual from *choosing* freely. Freedom of action is determined by non-judicial *external* constraints. As illustrated in the previous example, these constraints will include things like being locked in a cell or lacking a key to start an engine. In such scenarios the individual is unable to *act* freely because the non-judicial external circumstances prevent her from driving her car.

Hindrances to freedom of action will also include the intentional and unintentional interferences of other individuals. A person cannot act freely if another individual has intentionally hidden her car keys. Nor can she act freely if another individual has unintentionally lost her car keys. Restrictions on freedom of action thus include circumstantial, intentional and unintentional interferences on action external to the individual.

### ***3.1.4 Autonomous Persons and Free Choices***

In order to understand the nature of free choice it is helpful to draw a distinction between autonomous choices and autonomous persons. Faden and Beauchamp have argued that autonomy should be measured in terms of the autonomy of the decisions made rather than as a feature of a person. They draw a distinction between autonomous persons and autonomous decisions because they plausibly claim that nonautonomous persons can occasionally make autonomous choices:

Somewhat paradoxically, autonomous actions can be performed not only by by [sic] *autonomous persons* – those who generally, but not always, act autonomously – but also (on some occasions) by *nonautonomous persons* – those who generally, but not always, fail to act autonomously (Faden and Beauchamp, 1986: 235).

An example of a case in which a person might be thought to be generally nonautonomous but successfully makes an autonomous decision is of a person suffering from amnesia. This individual may be considered generally nonautonomous because she has significant lapses in her memory and so is unable to make autonomous decisions

that depend on knowledge of her values or interests.<sup>27</sup> However she is likely to be able to make the occasional autonomous decisions regarding trivial issues such as what she would like to eat, or how she would like to have her hair cut.

Likewise, autonomous persons can sometimes make nonautonomous choices, owing to temporary interferences with their decision making (Faden and Beauchamp, 1986: 8). Indeed, although an autonomous person can generally make autonomous decisions within her personal domain, she may not be able to make autonomous decisions in situations in which she lacks expertise. Alternatively, she may not be able to make an autonomous decision if, for example, she is being threatened to make a certain choice, or indeed hypnotised into making a particular decision. Whilst she is generally thought of as an autonomous person not all of her decisions will be autonomous.

### ***3.1.5 The Capacity for Autonomy***

In contradistinction to ‘freedom of action’, in which an agent is free from external constraints on her actions, ‘freedom of choice’ is measured in terms of the presence or absence of *internal* constraints on an individual’s ability to make decisions (Feinberg, 1986: 64). Feinberg has analysed the word ‘autonomy’ as having four closely related but distinct meanings:

...it can refer either to the *capacity* to govern oneself, which of course is a matter of degree; or to the *actual condition* of self-government and its associated virtues; or an *ideal of character* derived from that conception; or (on the analogy to a political state) to the *sovereign authority* to govern oneself (Feinberg, 1986: 28).

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<sup>27</sup> The notion that we should be concerned with autonomous actions rather than autonomous persons parallels the distinction between global and task-specific competence outlined in section 2.2

The internal conditions for freedom of choice will be understood here in terms of the capacity for autonomy (from hereon AC) as opposed to a condition, ideal of character of as denoting an authority.

The internal conditions of freedom of choice (AC) should not be conflated with what I later refer to as 'exercisable free choice'. Wilkinson and Moore have made a similar distinction in their discussion of inducement in research (1997), arguing that informed consent procedures are in place to protect patient autonomy rather than patient freedom claiming that a lack of freedom does not undermine autonomous informed consent:

If the sole alternative to death is some lifesaving treatment, then one is unfree to turn it down, but this does not rule out autonomous choice of the treatment. All the features of autonomous choice might be present: careful deliberation, correct understanding of the options, no manipulation, and so on. If informed consent is possible, despite the dire choice one faces, it cannot be because one is free to refuse the treatment. It must be because one can nonetheless act autonomously. We conclude that doctrines of informed consent aim to protect autonomy, not freedom (Wilkinson and Moore, 1997: 377).

The claim here is that informed consent procedures protect the individual's autonomous choices and not her freedom. Wilkinson and Moore's term 'autonomous choice' equates with my concept of AC and the internal ability to freely choose: "[s]kating over many complications, a person is autonomous when she decides what to do for herself"(Wilkinson and Moore, 1997: 377). Additionally their term 'freedom' equates with my theory of 'exercisable free choice' (explained fully in section 3.2). Unlike Wilkinson and Moore I argue that informed consent procedures should protect

exercisable free choice, rather than AC, in order for such choices to be meaningful. (as defended in section 3.1.1).<sup>28</sup>

AC is important for developing an account of free choice since it is not possible to have the right to have one's decisions respected in medical practice if one does not have the internal ability to make free choices: "...it does not seem possible either to achieve the condition or to possess the right while lacking (totally lacking) the capacity" (Feinberg, 1986: 28). The nature of the internal conditions of free choice is complex and will be explored in detail in chapter 4. For the remainder of this chapter, AC will be used as a placeholder for the internal ability to govern one's choices.

### ***3.1.6 The Relationship between Freedom of Action and Freedom of Choice***

A distinction should be made between the condition of free choice and the *exercise* of freedom of choice. Whilst the ability to freely choose will depend on the internal capacity for autonomy (section 3.1.5) the exercise of free choice bears a more complicated relationship with freedom of action.

Having the freedom of choice will be of little use if the individual completely lacks freedom of action. Indeed, it is curious to suppose that one is able to exercise freedom of choice when one is externally prevented (non-judicially) from acting on any freely formed choices. For instance, although an individual may be able to exercise her free choice such that she is free to choose an expensive medical treatment from a range of

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<sup>28</sup> I also reject the supposition that free choice should be equated with the mere ability to pick out an option, regardless of the nature of those options, in section 4.1 and my discussion of minimal accounts of AC.

options, she will be unable to exercise her freedom of choice if she is unable to pay for the treatment. Her mere ability to make a free choice does not guarantee that she will be able to exercise her freedom of choice – for this, she will need freedom of action, or in this case, enough money.

### **3.2 EXERCISING FREEDOM OF CHOICE**

As noted in sections 3.1.5 and 3.1.6 a distinction should be made between the internal condition of free choice and the *exercise* of freedom of choice. Whilst the ability to freely choose will depend on AC (section 3.1.5) the exercise of free choice bears a more complicated relationship with freedom of action (section 3.1.3), de jure liberty (section 3.1.1) and de facto liberty (section 3.1.2). Indeed, as I will outline, both the presence or absence of legal prohibitions and permissions (de jure liberty and de facto liberty) and external constraints on action (freedom of action) significantly impact an individual's ability to exercise her freedom of choice.

First, an individual's ability to exercise her freedom of choice may be extended or limited by the presence or absence of laws and rights (sections 3.1.1 and 3.1.2). For instance, if an individual is in a situation where she has no de jure liberty, such that all possible actions or choices are legally prohibited, then the fact that she lacks any *internal* constraints on her choice-making and so has AC, would provide little assistance in legally exercising her freedom of choice.

Equally, an individual might have maximal de jure liberty, such that all possible actions and choices are legally permitted, but fail to meet the internal condition of AC. The absence of judicial constraints will be irrelevant to those who lack AC (section 3.1.5) since they will lack the internal capacity to make free choices. Consequently, an individual cannot *exercise* her freedom of choice, *even* in a completely judicially open society, if she is not able to exercise her autonomy internally.

Since the exercise of free choice requires more than having AC, a more precise account of what is involved in exercising free choice needs to be formulated in light of the interconnected concepts of de jure and de facto liberty and freedom of action. To start, let us state that a person is able to *exercise* freedom of choice when:

(1) She has AC

(2) There are no external non-judicial constraints preventing her from acting on her choices

Further, the exercise of freedom of choice as stipulated by (1) and (2) will only be legally upheld either if:

(3) There are no judicial constraints preventing her from acting on her choice (de facto liberty) OR

(4) She is judicially permitted to exercise her choice (de jure liberty)

We can thus measure an individual's freedom to exercise her choice in terms of conditions (1) and (2), and judge her legal freedom in terms of conditions (3) and (4). We can also specify that if condition (2) is absent in a given situation then the agent lacks any *real* choice since she is unable to act on the choice she makes internally. Additionally, we can stipulate that if both conditions (3) and (4) are absent in a given situation, then the individual lacks any real choice in a *legal* sense. An individual's freedom of choice may thus be constrained by both judicial and circumstantial restrictions on how she may exercise AC.

Within medical practice, a patient's freedom to *exercise* her choice can be measured in terms of whether she has AC and the treatment options she has available to her in terms of circumstance and law. If the free choices of patients are to be respected then medical practitioners will be required to (1) check that patients have AC (2) that there are no external restrictions on the exercise of her free choice (such as when a drug or treatment is too expensive) and (3) that there are no judicial limitations on the exercise of her free choice (for example, the patient is not legally permitted to exercise her free choice to be euthanized).

The nature of AC will be explored later in chapter 4. However, the possible non-judicial and judicial restrictions on the exercise of patient choice can be clarified here. Firstly, the patient's ability to exercise freedom of choice will depend upon certain non-judicial variations in the practices and services of different health authorities. For example, those who live in an area in which a specialised treatment is available have more opportunities to *exercise* their free choice (in the sense that they are able to act on their

choice to have the specialised treatment), unlike those who live in an area where the same specialised treatment is not available. When they use their freedom of choice to make a decision about what treatment they want, individuals falling under the former health authority have more opportunities to exercise their freedom of choice than those in the latter. Likewise, the latter area have a restriction on the *exercise* of their freedom of choice, because the possible action of using the specialised medical treatment is unavailable to them. If the *exercise* of patient choice is held to be of value, then external impediments to the exercise of free choice ought to be prevented.

Judicial restrictions on the exercise of patient free choice will include legislation relating to certain medical procedures and treatments. For instance, current legal restrictions on abortion include:

- (a) The approval of two medical practitioners
- (b) Pregnancy not exceeded 24 weeks.
- (c) continuation of pregnancy would injure physical/mental health of the pregnant woman or existing children
- (d) Continuation of pregnancy would risk the life of the woman (no 2<sup>nd</sup> physician needed).
- (e) Substantial risk that the child will be born disabled (English, et. al., 2004: 242)

Female patients who fail to meet these conditions will not be able to legally exercise their choice to have an abortion in a medical setting.

I therefore analyse exercisable free choice in the domain of medical practice in terms of meeting conditions (1)-(4). A patient is able to legally exercise free choice in medical practice when:

(1) She has AC

(2) There are no external non-judicial constraints preventing her from acting on her choices

(3) There are no judicial constraints preventing her from acting on her choice (de facto liberty) OR

(4) She is judicially permitted to exercise her choice (de jure liberty)

Any future reference to the patient's 'exercisable free choice' in the remainder of my thesis will equate to the meeting of all four of these conditions.

### ***3.3 CONCLUDING REMARKS***

Chapter 3 has provided an account of 'exercisable free choice' which draws upon concepts of de jure liberty (section 3.1.1), de facto liberty (section 3.1.2), the capacity for autonomy (AC) (section 3.1.5) and freedom of action (section 3.1.6). De Jure liberty and De Facto liberty were used to denote the presence or absence of judicial licence whilst AC was presented as an internal condition to make free choices. Moreover, I argued that this internal capacity to make free choices should not be conflated with exercisable free choice: whilst AC is characterised as the ability to make a decision, exercisable free choice is the ability to make a decision that can be legally and circumstantially acted

upon. Although within this chapter AC has been used as a placeholder, a full account of AC is developed in the following Chapter.

My final definition of legally exercisable free choice required the satisfaction of four conditions, specifically that the individual has (1) AC, that (2) there are no external non-judicial constraints preventing her from acting on her choices, that (3) there are no judicial constraints preventing her from acting on her choice (de facto liberty) OR that (4) She is judicially permitted to exercise her choice (de jure liberty). This is the conception of exercisable free choice that I will be referring to for the remainder of the thesis.

The purpose of the Chapter has been to develop a concept of exercisable free choice which can be used in order to explain and object to the position of absolutism (Chapters 5 and 6), the position that respect for competent patient choices is *always* more ethically important than upholding the duty of care. My definition of exercisable free choice is thus central to my rejection of the prioritisation of informed consent over the duty of care, and thereby my justification of hard paternalism (the reversal of this prioritisation) in Chapters 8 and 9.

## CHAPTER 4: AUTONOMY AS A CAPACITY

In Chapter 3 I developed an account of 'exercisable free choice'. One condition of this account was that the patient had the capacity for autonomy (AC). The focus of the following chapter is to expound three main conceptions of AC: minimal (section 4.1), procedural (section 4.2) and substantive (section 4.3). I will argue that both minimal and procedural accounts of AC fail as accounts of AC presenting a substantive account as successfully explaining both the value of exercisable free choice and thereby why respect for exercisable free choice can be used as a justification for informed consent procedures.

### ***4.1 MINIMAL AUTONOMY***

The minimal account of AC is most simply characterised as an agent's ability to pick out an option. On the minimal account of AC the *value* of autonomy is explained merely in terms of the ability to choose an option, regardless of the content of that choice or how it was formed. For the minimalist about AC we ought to respect an individual's choice if the choice was made by the individual herself (Wolf, 2005: 260). To clarify the position it is helpful to refer to an example:

Both Patient A and Patient B have been in a traffic accident and are in need of a blood transfusion in order to survive. Under the doctrine of informed consent both patients are asked whether they consent to receiving the treatment. Patient A spends a great deal of time thinking about the advantages and risks of the treatment, discussing it with his family and doctor, finally choosing to accept it because he thinks it will prolong his life. Conversely, Patient B follows his fearful gut reaction of disgust to the prospect of having foreign blood in his body and immediately declines the treatment.

According to the minimal account of AC not only are both Patient A and Patient B equally exercising AC - since they both have the ability to select a medical treatment option - but their decisions are also equally deserving of respect. Since it is the mere capacity to choose which is valuable, regardless of how that decision was formed or what its content happens to be, the proponent of minimal autonomy argues that both of their decisions ought to be respected.

However, the minimal account of AC is inadequate on three counts. Firstly the theory is unable to explain how AC is possible in light of theories of psychological determinism. The second two problems arise in response to the claim that a minimal account of AC shows what is valuable about free choice. In the first instance minimal AC fails to identify when the minimal capacity has been exercised, meaning that it cannot account for *when* informed consent procedures are justified. Secondly, the minimal account of AC is unable to explain *why* informed consent procedures are ethically valuable; we need some further reasoning in order to explain why we should respect the arbitrary decisions of patients as characterised by the minimal account of AC.

To begin with, Wolf has shown that the thesis of psychological determinism causes serious concerns for the minimal account of AC. Psychological determinism is the view that the constituents of an agent's psychology, including beliefs, values and reasons for action and choice, are a product of one's background and environment, and are therefore not of the agent's own creation (Wolf, 2005: 258). As Strawson notes, when we are interested in free actions (or in this context free choice) we are interested in actions

that are self-determined, rather than those that are performed due to 'reflex' or habituation (Strawson, 1994: 6).

The problem of psychological determinism for the minimal account of AC is that in order to establish whether or not a patient is choosing freely (in the sense that she is exercising AC) we must be able to make a distinction between choices that are self-directing from those that are reflexes or mindlessly habitual actions. For clarification, take a further example:

Patient C - unfortunate enough to be involved in the same traffic incident - is also in need of a blood transfusion which he decides to refuse. However, we can imagine that through his upbringing and education he has been psychologically determined to refuse the treatment. For instance, he may have been taught by his school teachers that blood transfusions are ineffective or by his religious community that they are forbidden. Because Person C has been educated and influenced in such a way that he is determined to refuse the blood transfusion he simply *has no choice* but to make that decision; he could not have chosen otherwise.

Problematically, if psychological determinism is true then it is hard to see the value of free choice on the minimal account of AC. Indeed, if patients are not in control of their choices Wolf has correctly pointed out that we seem to be unjustified in valuing their decisions:

If free will is an illusion and we are not calling the shots then these attitudes [of respect for free choice] appear to be inappropriate and unjustifiable, and so do the practices of reward and punishment, of credit- and discredit-giving that reflect and express these attitudes (Wolf, 2005: 259)

The minimal account of AC places value on a patient's choices because they are her own. However: "...if everything is determined, it is thought, then what happens, happens, whether we want it to or not" (Wolf, 1989: 141) and so it remains unclear as to whether the patient herself is picking out the option.

Moreover, regardless as to whether patients are psychologically determined, the minimal account of AC remains an unsuitable justification for informed consent procedures. Foremost, the minimal account fails to expose when informed consent procedures can be justifiably invoked in medical practice. Indeed, it is important to remember that the justification of informed consent procedures should be able to explain the distinction between choices that are freely made and those that are not and hence when the doctrine can be appropriately invoked. The minimal account of AC fails to provide us with enough information to make this distinction.

Firstly, the minimal account is unable to differentiate between patient choices that are freely made and those that are not because it fails to note that for all agents there is a distinction between desires that they want to keep and desires that they would rather not have. An agent may have desires which she regrets having, or feels unable to control – for instance: "...a desire for nicotine or even chocolate, a desire to sleep with one's best friend's spouse" (Wolf, 2005: 264). The minimal account thus needs to be developed in order to distinguish between agents who approve of their choice from those who regret the choice they have made because they feel as though they were not in control of making it in order for informed consent procedures to be applied in practice.

In the second place it is not clear on the minimal account *why* it is important to respect a patient's AC. The difficulty of determining why the ability to pick out an option is valuable has been explored by Manson and O'Neill. They have argued that the patient's mere ability to pick out a medical treatment option fails to show why autonomy is valuable, since: "...if we think of autonomy as a matter of *mere* choice, arguments will be needed to show why *all* choices (however irrational, however poorly informed) should be protected" (Manson and O'Neill, 2007: 20). They assert that the fact that an action is chosen does not inform us of the *reasons* why it was chosen. Such reasons are necessary for decision making as the fact that: "...some act is chosen is, after all neither necessary nor sufficient to justify doing it" (Manson and O'Neill, 2007: 185). Seemingly we cannot *ethically* justify informed consent procedures by: "...reducing morality to the arbitrary decisions of patients" (Lamb, 1995: 113). As presented, the minimal account of AC fails to identify anything unique or special about the ability to make a choice that is deserving of respect in informed consent settings.

Although minimal accounts of AC fail to clarify why autonomy, understood as exercisable free choice, is appealed to as a justification for the doctrine of informed consent, my analysis provides two criteria for assessing a theory of AC as a justification for informed consent procedures. What has been brought out is that in order for AC to be a justification for informed consent procedures:

- (1) the account needs to explain *why* AC is valuable and thus a justification for the doctrine of informed consent

(2) the theory needs to enable us to determine *when* informed consent procedures can be justifiably invoked.

My subsequent analysis of procedural and substantive accounts of AC will thus be measured against these two conditions.

#### **4.2 PROCEDURAL AUTONOMY**

Procedural accounts of AC improve on the minimal account by offering a way to differentiate between autonomous and non-autonomous persons. Instead of broadly defining AC as the capacity to pick out an option, the procedural account makes a distinction between first- and second-order desires in an agent's psychological make-up. For Frankfurt, an agent has AC when there is a qualifying relationship between her first- and second-order desires. An agent's first-order desire will relate to a particular choice that needs to be made: "...there are at the lowest level first-order desires to perform one or another action" (Frankfurt, 1987: 164). At the first-order level an agent's desire will have various possible options as its end. The subsequent level of desire on this schema is directed toward the agent's first-order desires: "[s]omeone has a desire of the second order...when he wants simply to have a certain desire" (Frankfurt, 1971: 16). A second-order desire will thus have as its content either the endorsement or rejection of particular lower-order desires. By making this distinction, Frankfurt is able to address the deficiency of the minimal account: namely, that it is unable to explain the difference between choices that are endorsed and choices that are regretted.

Once again, an example is useful to clarify this distinction: consider a patient, Andrew, who is required to take a foul tasting medicine in order to cure his illness. At a first-order level Andrew does not want to take the drug because its unusual flavour makes him feel queasy. He consequently has a first-order desire 'to avoid taking the medication.' However, Andrew also has a separate first-order desire 'to recover from his illness.' In order to exercise AC Andrew must deliberate on a second-order level and choose which of these two first-order desires he wants to constitute his choice. It may be the case, for example, that on a second-order level Andrew desires that his first-order desire to recover be acted on, and a desire that his first-order desire to avoid the medicine be overcome and not acted on. Andrew successfully exercises AC when he rejects his first-order desire to avoid taking the medication and endorses his first-order desire 'to recover from his illness.'<sup>29</sup> On Frankfurt's system Andrew's second-order endorsement of his first-order desire thereby constitutes the exercise of AC.

Important to procedural accounts is the qualification that only specific sorts of first- and second-order desires correspond to an agent's AC. The first-order desires that are constitutive of a person's free choice are those that *constitute* a person's *effective* first-order desires: "[w]hichever of these first-order desires actually leads to action is, by virtue of that effectiveness, designated the will of the individual whose desire it is" (Frankfurt, 1987: 164). The second-order desires which are necessary for constituting

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<sup>29</sup> The distinction between first- and second-order desires is not reducible to the difference between short and long term desires. For instance, it is possible for a heroin addict to have a long term first-order desire to take heroin (this is a likely situation given the addictive nature of the drug) and the occasional second-order desire to not want to take heroin (perhaps after bad experiences with the drug). Likewise, it is possible for an individual to have long-term second order desires and short-term first order desires: for example, she might have a long-term second order desire to want to lose weight, which is occasionally overridden by an impulsive, short-term, first order desire to eat chocolate cake.

an agent's AC are referred to by Frankfurt as second-order *volitions*. Second-order volitions will endorse what the agent intends to be effective first-order desire: "...A wants the desire to X to be among the desires by which, to one degree or another, he is moved or inclined to act" (Frankfurt, 1971: 15).

It is important to note that although second-order volitions are necessary for exercisable free choice they are not sufficient. This is because the effectiveness of one's volitions is dependent on (although not identical to) the agent's freedom of action. Indeed, it is possible for an agent to have a second-order volition without exercising freedom of choice – for example consider a case in which A has a second-order volition endorsing his first-order desire to eat some caviar. However, since he has no caviar to hand and lacks the funds to purchase any, his first-order desire cannot be effectuated *in spite of* his second-order endorsement of his first-order desire for caviar. In such cases, an agent's second-order volitions will be sufficient for AC, but not for exercisable free choice.

Gerald Dworkin refers to second-order endorsement of first-order desires as 'authenticity' (Dworkin, 1976: 25).<sup>30</sup> On the procedural account of AC an agent will only be autonomous if she is able to endorse or reject her first-order desires on a higher level of reflection and thus direct her action in light of her beliefs and values, thereby obtaining authenticity. Hence, for an agent to have AC she must have an effective first-order desire which has been buttressed by a second-order volition. On the procedural account of autonomy, an agent is thus autonomous if: "...he is free to want what he

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<sup>30</sup> Dworkin alters his theory of authenticity in (1988) arguing that: "It is not the identification or lack of identification [between higher- and lower-order desires], but the capacity to raise the question of whether I will identify with or reject the reasons for which I now act" (Dworkin, 1988: 15). However, his later complication of his theory does not alter the argument presented in this section.

wants to want” (Frankfurt, 1971: 20) and he accepts his first-order desire as part of his second-order set of desires beliefs and principles (Christman, 1989: 7). Again, the authenticity condition of AC will not be sufficient for having exercisable free choice, since an agent is able to endorse a first-order desire with a second order volition even if she cannot act on that desire.

Procedural accounts of AC have been met with heavy criticism. The three main critiques can be identified as:

1. The manipulation objection
2. The infinite regress objection, and
3. The ab initio problem

The manipulation objection (1) questions the authority of second-order desires. It is proposed that an agent’s second-order desire could be manipulated so that the agent has no control as to whether she endorses her first-order desires.<sup>31</sup> The crux of the problem is thus: “...whether [a] person is autonomous with respect to his second-order desire and, if he is, why this is so” (Taylor, 2005: 6). To build on a previous example of Andrew, it seems to be possible that a calculating hypnotherapist could manipulate Andrew so that his second-order desire to desire that his first-order desire to recover be acted on is

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<sup>31</sup> The manipulation problem is different to the possibility of psychological determination (section 4.1). It is possible for a compatibilist about free will to believe that an individual can exercise AC despite psychological determination just so long as those determining influences are not manipulative, i.e: “...one is not caused to act by any of a certain set of constraints (kleptomaniac impulses, obsession neuroses, desires that are experienced as alien, post-hypnotic commands, threats, instances of *force majeure*, and so on) (Strawson, 1994: 16). The manipulation problem thus focuses on only certain sorts of interference with individual choice.

replaced with a second-order desire to not want to desire to recover from his illness. If this manipulated second-order desire endorses his first-order desire to refuse the medicine then the decision to refuse treatment would constitute Andrew's AC. Problematically, even though Andrew would still pass the procedural requirement for having AC, since he has a second-order sanction of his first-order desire to avoid the drug, we should say that Andrew's choice is not free, since his second-order endorsement has been compelled by the motives and actions of the hypnotist. As Law correctly perceives:

[s]ome ways in which people acquire the standards by which they assess their first-order desires are such as to render them non-autonomous: they may, for example, have been brainwashed, or hypnotised or systematically deceived in certain ways (Law, 2003: 41).

Procedural accounts of AC can thus be objected to on the basis that an individual's second-order desires can be manipulated thereby failing to show why an agent's first-order desire is authentic.<sup>32</sup>

Frankfurt is aware of the manipulation objection, noting that it is unclear from his account why an individual's second-order volitions are autonomous in a way her first-

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<sup>32</sup> Manipulative influences on second-order desires have recently been defended as ethical when the outcome of such manipulation leads to the endorsement of desires that protect the individual's well-being. This defence takes the form of 'Nudge Paternalism' the position that an individual's desires can be justifiably influenced so that she is more likely to choose the better option (Thaler and Sunstein, 2003 and 2008) Thus, whilst her choice is nudged towards the better option and away from making reckless, uninformed and harmful decisions, the individual is not forced to make a particular choice: 'nudging' is distinguished from 'forcing' by the fact that people can still choose the de-emphasised option, if they really want to" (Anderson, 2009: 4). It should be recognised however that the manipulation problem extends beyond merely making it more likely that an individual will endorse one desire rather than another since it is possible that an agent's second order desire could be manipulated in such a way as to guarantee that she will endorse a particular first-order desire.

order preferences might not be (Frankfurt, 1987: 165). Dworkin is similarly alert to the problem that:

[s]econd-order reflection cannot be the whole story of autonomy. For those reflections, the choice of the kind of person one wants to become, may be influenced by other persons or circumstances in such a fashion that we do not view those evaluations as being the person's own (Dworkin, 1988: 18).

At this stage, the procedural analysis of AC fails to identify persons who have been conditioned or intensively educated to hold certain desires and so classes persons as having AC even if her second-order desires have been manipulated just so long as her lower-order desires are consistent with her higher-order desires (Christman, 1989: 9). The procedural account of AC as described so far thus fails since it does not successfully explain what is distinctive about the person who has AC as opposed to the person who lacks it and so it cannot be used in informed consent settings to determine whether an individual has AC and so is capable of exercising free choice.

As we will see, a futile response to the manipulation objection is the postulation of the existence of a third-order desire which monitors the authenticity of an agent's second-order wants. AC is thus claimed to be present, and the manipulation problem claimed to be avoided, by postulating the existence of a level of endorsement above the point of manipulation. For instance, we can imagine that Andrew has a third-order desire that he desires that he desires to take the medicine, thereby having third-order *regret* for his manipulated second-order endorsement of his first-order desire to avoid taking his medicine; in other words his authentic self does not want what he wants to want.

Nevertheless, this response to the problem of manipulation immediately leads to the second objection propounded against procedural accounts of autonomy that such accounts lead to an infinite regress (2) of increasingly higher-order desires. As Noggle nicely elaborates:

[I]f we regard it as implausible for an inauthentic element to impart authenticity to another element, then we will need to guarantee that this proposed authenticator ( $E_2$ ) is itself authentic before we can be sure that it can impart authenticity to some other element ( $E_1$ ). And this need will tempt us to posit yet another authenticator, the authenticity of which can then be questioned, and so on (Noggle, 2005: 92).

It is thus apparent that no matter how many higher-order desires are posited the question can always be raised as to whether that desire is authentic. The procedural account fails to define AC since it is possible that each level of desire could be manipulated no matter how many higher-order desires one posits into existence.

The third problem - the ab initio objection (3) - stems from the fact that the infinite regress objection cannot be resolved. Critics raising this third objection claim that it is unclear (or at the very least highly unintuitive) how a first-order desire obtains authenticity despite the fact that, given the infinite regress, it must be founded on an inauthentic desire: “[c]ertainly a person cannot be autonomous at a lower level of desire when those very desires are [possibly] the result of manipulation further up the hierarchy of preferences” (Christman, 1989: 9). At bottom, the ab initio problem denies that it is possible for a lower-order desire to be authenticated if there is no highest desire which itself can be authenticated.

According to Noggle, the *ab initio* problem makes the infinite regress problem ‘insoluble’ since it denies the claim that a higher order desire that lacks authenticity can impart authenticity upon a lower-order desire (Noggle, 2005: 92). The procedural account is thus faced with a dilemma. Either the hierarchy of higher-order desires goes on infinitely, or the highest-order desire is inauthentic. The *ab initio* problem is thus intended to show that authenticity is impossible because the only way to avoid the infinite regress problem is to suppose that the highest-order desire will be inauthentic. Since it is impossible to authenticate a lower-order desire with an inauthentic higher-order desire, the dilemma ostensibly proves that a procedural account of autonomy is wrong.

In order to avoid both the infinite regress and *ab initio* objections both Dworkin and Frankfurt propose to adopt an independent method for establishing the authenticity of highest-order desires. Although both argue for additional elements in determining the authenticity of higher-order desires, Frankfurt’s account remains strictly structural whilst Dworkin invokes historically causal factors (Anderson, 2008: 10). Frankfurt proposes that the authenticity of a second-order desire is guaranteed when an agent is *decisive* about the desire that he wants to constitute his will: “...a commitment is decisive if and only if it is made without reservation, and making a commitment without reservation means that the person who makes it does so in the belief that no further accurate inquiry would require him to change his mind” (Frankfurt, 1987: 168). According to Frankfurt a decisive commitment to a desire will ‘resound’ throughout an agent’s psychological structure guaranteeing the authenticity of an agent’s will by eliminating the possibility of any higher-order reflection. As Anderson clarifies: “I

am...autonomous, when I wholeheartedly endorse the motivations for my actions, where 'wholeheartedness' is understood as a state of the will that is untroubled by doubts or by a desire to change" (Anderson, 2008: 12). With 'decisive' or 'wholehearted' identification the question concerning a higher-order level of identification does not arise, thereby avoiding the infinite regress and *ab initio* objections.

Nevertheless, the condition of 'wholeheartedness' appears to remain open to the manipulation objection, since it certainly seems possible that an agent's 'decisive commitment' could have been inculcated by a manipulative influence.<sup>33</sup> It is not obtuse to suppose that Andrew's hypnotist could have manipulated him into 'decisively committing' to his first-order desire to avoid taking his medicine. Such 'wholehearted' desires: "...could still be the result of the agent's succumbing to forces that are external to her" (Taylor, 2005: 8). Frankfurt's additional element to his procedural theory of AC thus remains unsatisfactory since it does not avoid the manipulation objection. Worse still, since Frankfurt's account is prone to the manipulation problem his account is also still open to the dilemma posed by the infinite regress and *ab initio* objections. As Taylor agrees: "...the mere fact that a person has *decisively* identified herself with a particular first-order desire does not halt any possible problematic regress" (Taylor, 2005: 8). The opportunity for manipulated 'decisive commitments' clears the way for an infinite regress of higher-order preferences which aim at authenticating the decisive commitment. Once again, if the infinite regress objection is denied by positing an

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<sup>33</sup> Notably, Frankfurt does not claim that a decisive commitment is one that is absent of all conflict of desire. Indeed it is possible that a person possess wholeheartedness despite struggling against unwanted desires. To be wholehearted thus means that a person is: "...resolutely on the side of one of the forces struggling within [her] and not on the side of the other" (Frankfurt, 1999: 100), not that all of her desires are matched in terms of their content.

inauthentic highest-order desire, the account is consequently left open to the *ab initio* objection.

However, not only does Frankfurt's postulation of the existence of 'decisive commitments' fail to avoid the original three objections, a further epistemological difficulty can be directed against his theory. As Noggle correctly indicates, the postulation of a 'decisive commitment' that resounds through the agent's higher-order desires is 'somewhat mysterious' (Noggle, 2005: 90). As Frankfurt himself freely admits, it is, indeed, epistemologically problematic to determine *when* a second-order desire is wholehearted or decisive: "[i]t is *always* possible, in the deployment of any principle whatever, to make a mistaken or unwarranted judgement that the conditions for applying the principle correctly have been satisfied" (Frankfurt, 1987: 169). Hence, if a 'decisive commitment' is merely an agent's subjective endorsement of his desire then Frankfurt's account leaves open the possibility that an agent is mistaken about his desires and commitments.

To return to the running example, let us now imagine that Andrew (sans hypnotist) makes a decisive commitment to take his medicine despite his first-order revulsion at its taste. We might suggest that only Andrew can determine whether his desire is wholehearted or not; Andrew believes that it is and therefore thinks that it resounds through all of his higher-order desires. The question as to whether or not he wants to take his medicine simply does not arise on a higher-level of reflection. However, this seems to grant Andrew with a level of knowledge about his own beliefs and desires that we might not want to attribute to him. Indeed it is possible that Andrew has made a

mistake about what he wants – he might not have fully considered the implications of taking the drug, such that he will feel queasy and so will be unable to finish writing his book – or he might have deceived himself about the actual healing powers of the medicine due to some latent supernatural beliefs. It appears that despite Andrew’s contention that he is wholehearted about his second-order desire to take the medicine, he could be wrong. It is thus possible that a person’s belief that she is wholehearted in view of a particular higher-order desire could be mistaken. As Frankfurt notes, even in cases where an agent is apparently sincere about her desire it could still fail to be wholehearted: “...whether the person is aware of it or not, he has other intentions, intentions incompatible with the one the decision established and to which he is also committed” (Frankfurt, 1987: 174). Problematically for Frankfurt’s account, it thus seems that if it is the agent who determines that his desire is decisive then he must be either incapable of being influenced by subconscious or self-deceptive desires, or must have omniscient knowledge that he is not deceiving himself. We are thus left at a loss: “...as to how to distinguish between *being* autonomous and *thinking* one is autonomous” (Anderson, 2008: 14).

Frankfurt’s account thus fails to rebut the three main objections to procedural theories of autonomy or to provide an epistemologically plausible account of AC. Importantly, since one of the criteria for a suitable justification for informed consent procedures was that it could explain when such procedures could be justifiably invoked Frankfurt’s account of procedural autonomy fails. Indeed, even though it is possible that there exist agents with a wholehearted structure of will, since this is a feature of agents that is

epistemologically inaccessible this account of AC cannot be a justification for the invocation of the doctrine of informed consent.

As previously mentioned Dworkin, unlike Frankfurt, adds a historical element to his procedural account of AC in response to the three posited objections. In addition to the condition of authenticity (i.e. that a first-order desire has been endorsed by a second-order desire) Dworkin posits a second necessary condition of autonomy which he terms 'procedural independence': "...the notion of autonomy which should play a role in the evaluation of various methods of behaviour control is that which requires authenticity and procedural independence" (Dworkin, 1976: 26). A theory of procedural independence will characterize the way in which an individual's desires can be rightfully called authentic. According to Dworkin, an agent is autonomous not just when she has higher-order endorsement but when the background conditions from which the higher-order desire arose were not manipulative or coercive. Dworkin would thus deny that hypnotised Andrew is autonomous since the historical cause of his second-order desire was the hypnotist. Only desires which are authentic (endorsed by a higher level of desire) *and* appropriately caused constitutes AC.

In the attempt to avoid the problem of manipulation Dworkin's account also tries to avoid both the infinite regress and ab initio problems. Foremost, there is no longer a requirement to invoke higher-order desires to authenticate lower-order desires since the autonomous agent's second-order desire is guaranteed to be authentic if it has the correct causal history: "[w]ithout the requirement of another element to serve as an authentic authenticator, the regress seems to lack a place to get started" (Noggle, 2005:

94). Indeed, the buck stops with the authentic second-order desire which is appropriately caused. Similarly, the ab initio problem does not arise because an appropriately formed second-order desire will contain the authenticity that is to be imparted to lower-order desires.

However, despite this promising line of thought, Dworkin does in fact face the problem of manipulation. The problem stems from the contention that Dworkin only avoids the manipulation: "...by simply ruling *ex cathedra* that a person is not autonomous with respect to those desires that he has been manipulated into possessing" (Taylor, 2005: 5). In ruling out manipulative elements in the constitution of an agent's higher-order desires Dworkin's account simply ordains that some historical factors are constitutive of autonomy whilst some are not. What is thus lacking from his account is a positive explanation as to when a higher-order desire has been formed in a procedurally independent fashion. Worse yet, Dworkin merely outlines rough criteria for discovering what such a theory might explain:

Spelling out the conditions of procedural independence involves distinguishing those ways of influencing people's reflective and critical faculties which subvert them from those which promote and improve them. It involves distinguishing those influences such as hypnotic suggestion, manipulation, coercive persuasion, subliminal influence, and so forth, and doing so in a non ad hoc fashion (Dworkin, 1988: 19).

Problematically, unless Dworkin can explicitly state what the conditions for procedural independence are his theory of AC is still open to the manipulation objection. This is because Dworkin is unable to make a distinction between simply giving an agent advice about what they should do and manipulating them. For example, we might say that

Andrew's second-order volition endorsing his first-order desire to preserve his health is procedurally independent. However, it is likely that in forming this volition Andrew will have been influenced by learning about the effectiveness of medicine, the value of health and by considering the needs of members of his family dependent upon him. It is not clear on Dworkin's account why this kind of influence does not constitute a violation of procedural independence, while hypnotic suggestion does count as such a violation, in a way that is not ad hoc. Moreover, some cases of hypnotic suggestion might preserve an agent's AC when they are freely chosen: for instance hypnosis services for individuals desiring to quite smoking or to lose weight. However in order for Dworkin to make the distinction between autonomy preserving hypnosis and autonomy diminishing hypnosis he must rely on forms of hypnosis chosen by the individual, thereby covertly relying on individual desires and rendering procedural independence as obsolete. For these reasons, Dworkin is unable to counter the manipulation objection because his theory offers no way of discerning when a higher-order desire was formed in a procedurally-independent fashion. Although Dworkin claims that procedural independence is present when: "...a person's reflections have not been manipulated, coerced, and so forth" (Dworkin, 1988: 20) he does not provide a means of discerning when a desire is manipulated in such a way as to undermine AC. Dworkin thus fails to save a procedural account of autonomy by adding a condition of procedural independence to his condition of authenticity.

Furthermore, Dworkin is unable to meet the constraint of offering an account of AC which is able to determine when informed consent procedures are justified. Indeed, since we have no way of evaluating whether an agent's higher-order desire is

procedurally independent we have no way of discerning when a patient's decision ought to be respected. Despite explaining why AC is *valuable*, neither Dworkin nor Frankfurt's account of procedural autonomy offer a suitable justification for informed consent procedures.

### **4.3 SUBSTANTIVE AUTONOMY**

As we have seen, the main failing of the procedural account of AC is that it fails to explain when decisions are autonomous and thus deserving of respect. Wolf similarly proposes that the procedural accounts are not a suitable solution to the problem of determining when respect for free choice should be offered.<sup>34</sup> To see why the procedural account of fails to account for AC and thus why it is valuable Wolf uses the example of JoJo:

JoJo is the favourite son of Jo the First, an evil and sadistic dictator of a small undeveloped country. Because of his father's special feelings for the boy JoJo is given a special education and is allowed to accompany his father often and observe his daily routine. In light of this treatment, it is not surprising that little JoJo takes his father as a role-model and develops values very much like his dad's. As an adult, he does many of the same sorts of things his father did, including sending people to prison or to death or to torture chambers on the basis of the slightest of his whims. He is not *coerced* to do these things; he acts according to his own desires. Moreover, these are desires that he wholly wants to have (Wolf, 1989: 143).

The reason that the example of JoJo undermines the procedural account of AC is that although he conforms to Dworkin's criteria of authenticity since "[f]rom the inside, he feels as integrated, free and responsible as we do" (Wolf, 1989: 144), we still don't want

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<sup>34</sup> The following discussion relies on Wolf's theory of responsibility in order to account of the purported value of AC, although Wolf herself does not refer to her position in this way. Section 4.3 thus provides an interpretation of how her theory would apply in the context of determining whether a patient has AC and so whether she has the capacity to exercise free choice.

to accord his decisions or choices with any positive value. Perplexingly, the problem cannot be avoided by claiming that JoJo's desires are not up to him. Indeed as was pointed out with Dworkin's theory, a distinction cannot be drawn between procedurally independent and procedurally dependently formed desires.

Wolf develops her substantive theory of AC by maintaining that although the conditions of authenticity (higher-order endorsement of a lower-order desire) offered by the procedural accounts of AC are necessary, they are not sufficient (Wolf, 1989: 145; Wolf, 1990: 7). This is in fact something on which Dworkin and Frankfurt agree, and is the motivation for their failed attempts at invoking conditions of 'procedural independence' or 'whole-heartedness' respectively. However, instead of proposing a further procedural or historical condition of autonomy, Wolf instead appeals to a normative condition.

Rather than depending on a 'metaphysical' theory of autonomy, such as those of Frankfurt and Dworkin, Wolf argues that we have a *normative* reason to save our practices of ascribing value to AC so that: "...the metaphysical truth about the world and our relation to it is not such as to imply that we are not responsible beings" (Wolf, 2005: 259). Wolf thus attempts to account for the ethical value of AC but without referring to an impossible metaphysical property of procedural autonomy and instead to a normative ability.

To begin with, Wolf explains that the case of JoJo indicates that there is a significant difference between the desires of authentic selves (which have the appropriate endorsement between higher and lower order desires) which can be evaluated as being

Bad, and those for whom the content of their authenticated desires can be called Good, thereby committing to an objectivity of value (Wolf, 1990: 118). She thus presents an account of responsibility which is compatible with psychological determinism; although the values of authentic selves are always determined we can still distinguish between persons who have AC and persons who do not by looking at the normative content of their values and desires.

Wolf's motivation for drawing a distinction between Good and Bad authentic selves is based on our current practices of respecting agents' choices. Indeed, in terms of designations of responsibility we are inclined to exempt persons from blame if they had no control over their bad authentic selves. Conversely, we are not apt to withhold praise from good authentic selves. Wolf is thus inclined to suggest that persons who have no control over their bad authentic selves should be exempt from blame, whilst praise should not be withheld from good authentic selves even if they too have no control over its formation: "...it seems crazy that this should be a reason to withhold the praise or credit that we initially judge them to deserve" (Wolf, 2005: 268).

According to Wolf the relevant difference between Good and Bad authentic selves which have been equally determined to be so is that the former are able to act through *Reason* whilst the latter have been psychologically shaped in such a way as to render them unable to act in accordance with Reason. Specifically, the good authentic self is able to act in accordance with reason because she desires to be sane: "...a desire that one's self be connected to the world in a certain way" (Wolf, 1989: 144). What is thus praiseworthy about the good-acting agent is that her authentic self has been developed

in such a way that she is capable of acting in light of her Reason. On the other hand, the bad-acting agent is exempt from considerations of responsibility and blame because he is *unable* to act in accordance with Reason. In the context of this chapter, the fall-out of this theory is that only the Good authentic choices of individuals are deserving of respect, whilst the Bad authentic choices of individuals are not.

The benefit of Wolf's position is that it is compatible with psychological determinism, since the sources of our ability to reason: "...are as external as are the forces that inhibit and interfere with it" (Wolf, 2005: 270). Wolf can thus explain the ethical value of AC despite the manipulation problem: although the method of authentication might have been manipulated, the relevant feature of AC which makes it worthy of respect is its normative content – specifically, whether the agent has made a Good or Bad choice, a Good choice being one that is made in light of Reason.

However, as an ethical justification for informed consent procedures the Wolfian account is controversial. On Wolf's theory, whether an agent with AC's choice is worthy of respect depends upon the normative content of the particular choice she makes: if it is a Good choice then the choice ought to be respected. On the other hand, if it is a Bad choice then we have no reason to respect the individual's choice. The consequence of this theory as applied to medical ethics and the doctrine of informed consent is that only the Good decisions of patients should be respected.

Concerns over the Wolfian account of AC may be raised because – since humans are fallible – our judgements as to whether or not an individual's choice is Good or Bad

might be wrong. Indeed, we may be mistaken in judging that a patient's choice was not made in light of the True and the Good and so with Reason. In that case, we might fail to respect an individual's choice because we falsely believe that her decision is a Bad one. Those who value AC for the reason of ideological neutrality (as put forward by Dworkin in section 4.2) might be justifiably wary that judgements as to whether or not an individual's choice is Good or Bad could be mistaken (Wolf, 1989: 149).

Wolf's own response to this worry is modest. She claims that the distinction between Good choices and Bad choices can be made because of: "...widespread intersubjective agreement and the considerable success we have in getting around in the world and satisfying our needs" (Wolf, 1989: 149). Thus, although we cannot be *certain* that we always correctly judge that an individual's choice is Good and so worthy of respect, or Bad and so unworthy of respect, Wolf relies on her claim that we have enough intersubjective agreement so that our distinction between Good and Bad choices is not entirely arbitrary. Certainly, this appeal to intersubjective agreement might be inadequate to opponents of the theory: indeed, it seems possible that a large group of people might get the judgements between Good and Bad choices wrong: for instance, wide-spread intersubjective agreement that medical treatment is bad for one's health does not make it so. Due to the weakness of this response I present my own theory of how good and bad choices can be determined in my account of best interests in section 7.5, in which I also provide a further reason to reject dependence on intersubjective agreement about the nature of Good choices (section 7.5.1).

Leaving the issue of determining the normative content of Good and Bad choices until chapter 7, I will take it that the Wolfian account of AC should be accepted on the basis of

the inadequacies of the minimal and procedural accounts to explain the value of AC. The reason for this is that the account provides (albeit at this point incomplete) answers to the two conditions for an AC to be an adequate justification for informed consent procedures. Recall the conditions stated above:

- (1) the account needs to explain *why* AC is valuable and thus a justification for the doctrine of informed consent
- (2) the theory needs to enable us to determine *when* informed consent procedures can be justifiably invoked.

The Wolfian account meets condition (1) because it explains why AC is valuable. Unlike the procedural account, which was unable to successfully avoid the problem of manipulation, the Wolfian account by-passes the manipulation problem by pointing to the normative difference between Good and Bad choices. AC is valuable if the content of the choice is a good one made in line with the Good: it does not matter how that choice formed.

Secondly, the Wolfian account meets condition (2): informed consent procedures can be justifiably invoked when the patient makes a Good choice. The consequence of this is that patients who make bad choices are not protected by the doctrine of informed consent, and so their decisions can be overridden. Although I have noted that this point is controversial, the ability of the Wolfian account to explain why AC is of value (unlike minimal and procedural accounts) means that this is simply a consequence of looking

for an ethical justification for informed consent; informed consent procedures cannot be ethically justified on the basis of procedural or minimal accounts of AC.

#### ***4.4 CONCLUDING REMARKS***

In this chapter I have provided an account of autonomy as a capacity (AC), one of the features outlined as being required for exercisable free choice in Chapter 3. I have provided argumentation for rejecting the minimal account (section 4.1) and the procedural account (section 4.2) of AC. The minimal account was rejected because the position is vulnerable to the problem of psychological determinism and so is unable to determine whether or not an individual's choice is her own or whether it is determined by arbitrary factors. It was thereby shown to be unable to explain the ethical value of informed consent procedures. The procedural account of AC was criticised on three grounds: 1. the manipulation problem, 2. the infinite regress problem and 3. the ab initio problem. Possible responses to these criticisms, such as Frankfurt's condition of 'wholeheartedness' and Dworkin's theory of 'procedural independence' were rejected. Finally I defended a substantive account of AC on the basis that it explains both why AC is valuable and when informed consent procedures can be justifiably invoked.

The adoption of a substantive account of AC has significant consequences for my account of exercisable free choice, since an individual is only capable of exercising free choice when she makes her decisions in light of the Good. This account is therefore more restrictive than traditional accounts of free choice (which claim that the individual is free to choose anything), since it places a normative constraint on the sorts of free

choices that can be made. A detailed account of nature of the Good, in terms of individual well-being is presented in Chapter 7. In the intervening chapters I will incorporate the substantive account of AC into the definition of exercisable free choice developed in Chapter 3.

## CHAPTER 5: ABSOLUTISM

As explained in section 1.3 the doctrine of informed consent prioritises the value of exercised free choice above the duty of care. This *absolutism* about the ethical importance of respecting free choice demands that: "...if a person is acting autonomously and is the bearer of an autonomy right, then his or her choices morally ought never to be overridden by considerations of beneficence or proper care" (Faden and Beauchamp, 1986: 19). In chapter 1 we saw that medical practice is governed both by respect for patient free choices and the duty of care. Furthermore, it was shown that these two ethical goals can come into conflict (1.4). In Chapter 3 an individual was defined as having exercisable free will just so long as she has (1) AC (defined in Chapter 4 as substantive AC), that (2) there are no external non-judicial constraints preventing her from acting on her choices, that (3) There are no judicial constraints preventing her from acting on her choice (de facto liberty) OR that (4) She is judicially permitted to exercise her choice (de jure liberty).

According to the absolutist, when these conditions are met, a patient's free choices cannot be interfered with on the basis of other ethical considerations. When (1) respect for patient free choice and (2) the duty of care come in to conflict, the absolutist will claim that respect for patient free choice should always outweigh the duty of care. In this sense the ethical value of exercised free choice is thought to be inviolable. The position of absolutism will thus be preliminarily characterised as follows:

*Exercisable free choice has ethical priority and is protected by maximal respect for individual choices*

Accordingly, the absolutist claims that exercisable individual choices must always be respected.

Recently writers such as Julian Savulescu have assumed a model of absolutism in order to defend a legalised market in organs. He claims that: “[p]eople have a right to make a decision to sell a body part...To ban a market in organs is...to constrain what people can do with their own lives” (Savulescu, 2003: 138-9). According to Savulescu’s absolutism, individuals should be allowed to sell their body parts because they have a privileged right to freely choose what to do with their lives.

The mistaken assumption of absolutism in bioethics is thus that: “...ethics is served if autonomy is respected and...this is done by a fully informed choice (to consent or not)” (Widdows, 2011: 88). The absolutist claims that exercisable patient free choice *always* has priority over other ethical concerns such as exploitation, well-being and health. It is thus claimed that respect for patient decisions must be absolute.

I will argue in chapter 6 that the assumption that respect for patient choices is an ethical guarantor in cases where it comes into conflict with the duty of care cannot be sustained. However, before the objections to absolutism are presented, it is necessary to present the scope and limitations of the absolutist thesis since the difficulties of heralding respect for patient choice as an ethical guarantee cannot be adduced until it is clear what kind of exercisable free choices the absolutist claims are deserving of

unwavering respect. However, within this chapter I will simply outline the position of my opponent in more detail.

### ***5.1 THE HARM PRINCIPLE***

Although it may seem contradictory to present absolutism – maximal respect for individual free choice – as having limitations, these restrictions are accepted by absolutists in order to make their position coherent. John Stuart Mill is recognised as developing one of the central limitations on absolutism with ‘the harm principle.’ Mill argues that individual choice should be respected so long as it does not injure the interest(s) of another (Mill, 2008: 83). As a result, the state is permitted to interfere with an individual’s choices: “[a]s soon as any part of the person’s conduct affects prejudicially the interests of others” (Mill, 2008: 83). Whilst actions which cause no harm to others are regarded as expressions of individual free choice – and so for the absolutist deserving of respect – actions that cause harm to others are classed as being wrongful (Epstein, 1995: 369). According to the harm principle it is thus justified to limit individual exercisable free choice if the exercise of that free choice would cause harm to other persons.

In the following I will leave aside disputes about the logical scope of the harm principle. For instance, it has been argued that the Millian harm principle consistently leads a complete restriction on individual choice because interests are so various that it would be impossible to act without harming anyone’s interests. As Taylor notes:

...there are men who have a deep interest in such things as religion, patriotism, public manners, the preservation of wildlife, and so on, without end. Now if we say that no one shall be permitted to do anything that would foil, frustrate, or damage any such interest held by anyone, this will be about equivalent to saying that no one may do anything at all (Taylor, 1982: 58).

It is thus contended that the harm principle does little to protect individual liberty because it is likely to constrain all individual action.

Further, it has been argued that the harm principle can be misappropriated and so has been wrongly used by governments to justify increased intervention with individual action. Epstein presents the case that the harm principle has been used as: "...an engine of social control that is said to justify government intervention in all its manifestations" (Epstein, 1995: 371). Similarly, Harcourt has argued that the harm principle has been variously used to justify legal restrictions on: "[p]ornography, prostitution, disorderly conduct, homosexuality, intoxication, drug use, and fornication" (Harcourt, 1999: 181). Nevertheless, although the harm principle has been held in contention in a multitude of ways the attack I mount against absolutism does not bear on these intricacies. Rather, the harm principle is simply presented as a feature of absolutism in order present a reasonable outline of my opponent.

Crucially, in order for the harm principle to function it is essential to define what constitutes harm for the absolutist. The common-or-garden understanding of harm includes things such as the threat or infliction of physical injury such as an assault or a battery, and psychological injury including bullying, threats or verbal abuse. Harm can also be understood to include material losses, exploitation, or loss of loved ones. On the

ordinary conception, the concept of harm thus covers physical, psychological, monetary and familial injuries, threats or losses.

Importantly, the absolutist's harm principle relies upon a different conception of harm to our everyday usage of the term. For the purpose of differentiating between the ordinary and absolutist understanding of the term harm, I thus refer to the absolutist conception as 'harm\*'.<sup>35</sup> According to the absolutist an individual is only harmed\* if her interests are interfered with without her consent. Harm\* is thus defined in terms of the legal maxim *volenti non fit injuria* - a person is not wronged by that to which he consents (Feinberg, 1986: 11). The absolutist's motivation for developing the concept of harm\* is to be consistent with her claim that the ethical value of exercisable free choice is prior to all other ethical concerns. Indeed, as repeatedly noted (sections 1.3 and 2.1), according to the absolutist the individual is free to live her life as she sees fit, regardless of the harmfulness, riskiness or imprudence of her choices. The absolutist definition of harm\* is thus specialised since if the individual consents to an action that is contrary to other ethical values – as she does when she makes a decision which conflicts with the duty of care - then although we might view that decision as harmful, it does not constitute a harm\*. In order to clarify what is understood by harm\*, consider the case of organ selling:

Fred is facing financial difficulties and is unable to support his family. Given his current circumstances (he is unable to find alternative sources of income) Fred only has two options available to him: (1) he can sell one of his kidneys for financial gain, (2) let his family perish.

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<sup>35</sup> For the time being I grant this conception of harm\*. This is so that my rejection of absolutism in chapter 4 is based on an accurate understanding of the position. I return to the notion of harm\* and present some of its inadequacies in section 7.4.

According to the absolutist, Fred is not harmed\* if he consents to the surgery and to selling his kidney, because according to the absolutist: 'a person is not wronged by that to which he consents.' For the absolutist, Fred will only be harmed\* if his kidney is removed from him without his consent since this would fail to respect his exercisable free choice.<sup>36</sup>

Leaving aside the questionability of equating harm\* with the absence of consent the position of absolutism should be advanced thusly:

*Exercisable free choice has ethical priority and is protected by maximal respect for individual choices **on the condition that the interests of other individuals are not harmed\****

## **5.2 THE DOMAIN OF PERSONAL SOVEREIGNTY**

What is gained from the harm principle is the idea that each individual has a separate domain in which their authority reigns. Since a person is harmed\* if her interests are affected without her consent, absolutism requires that: "...each of us has separate domains, and no one is allowed to simply butt in to some domain properly reserved to another" (Epstein, 1995: 369). The thesis of absolutism – that individual choices deserve maximal respect – only applies to individual choices falling within the sovereign

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<sup>36</sup> It is important to note that the upsetting nature of the options open to Fred leads to alternative analyses of his situation. Indeed, as often is the case, the absolutist may argue that Fred could never have exercisable free choice in this situation because the context *demand*s that he saves his family and so sells his kidney. He is thus forced into picking an option that he otherwise would not have and for this reason – it is claimed – Fred does not freely consent to the procedure. Alternatively, I will argue that it is in fact possible that Fred could freely choose to sell his kidney (in accordance with my definition in chapter 2): however the nature of Fred's options are such that the harm that either option cause him (in the ordinary sense) is more ethically significant than whether or not he is harmed\*.

domain. Thus, an individual will have personal sovereignty over: "...all those decisions that are 'self-regarding,' that is which primarily and directly affect only the interests of the decision maker" (Feinberg, 1986: 56). For the time being it will be supposed along with Feinberg that a 'serviceable distinction' between self- and other- regarding action can be made (Feinberg, 1989: 56).<sup>37</sup>

According to the absolutist the personal domain of self-regarding action is drawn in terms of the individual's bodily and privacy rights. Firstly, the bodily domain refers to the authority an individual has regarding what happens to and what she does with her body. Thus, if I decide to get a large tattoo the absolutist will argue that the decision is rightfully mine; because it is *my* body I can authoritatively decide to modify it in this way. Moreover, I also have authority over what others may do to my body. This aspect of the bodily domain is pertinent to medical practice in which medical practitioners may need to interfere with an individual's body for diagnostic or surgical purposes, or even with the prescription of medication. Since the absolutist claims that the individual is sovereign over her bodily domain the medical practitioner must obtain the patient's consent before carrying out procedures on her body, in line with the harm\* principle.

Furthermore, as a sovereign over her body, absolutism permits the individual to consent to actions which may be injurious or harmful to her body in the ordinary sense. For example:

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<sup>37</sup> Note that this is only in order to set up my opponent accurately, and although whether or not such a distinction can be made is controversial because 'no man is an island', and every decision is bound to have some 'ripple-effect' on the interests of others (Feinberg, 1989: 56). However I will not be addressing this particular point of dispute within my thesis.

If a man or woman voluntarily chooses to have a surgical operation that will render him or her infertile and a physician is perfectly willing to perform it, then the person's 'bodily autonomy' is infringed if the state forbids it on some such ground as wickedness or imprudence (Feinberg, 1986: 53)

In Feinberg's case, the person *choosing* to have this surgery ought to have her decision respected because the damaging consequences of the surgery will only affect her body, thereby falling within the domain of personal sovereignty.

It would appear that there are more constraints on what happens to my body other than what I consent to. For instance, one can only consent to sexual intercourse above a certain age, and one cannot consent to being killed. My definition of exercisable free choice takes this into consideration since it is possible for someone to fail to exercise free choice when there are judicial or circumstantial factors placed on her actions. The absolutist can thus explain these constraints in terms of the inability of the person in question to legally consent to these actions. Thus, we have an 'age of consent' for sexual intercourse because persons under the age of 16 are thought to be unable to consent to the activity: they do not meet the conditions of exercisable free choice. Similarly, it could be argued that it is impossible for anyone to freely choose to be killed. These further constraints on the sovereign domain are explained away by the absolutist by claiming that it is impossible for such persons to freely consent to these actions.

In addition to attributing individuals with an authority over their bodily domain, absolutists also draw the boundaries of personal sovereignty in terms of privacy rights. The 'Right to Privacy' is used by Feinberg to delineate the boundaries of personal sovereignty beyond decisions regarding one's body, including: "...the right to decide how

one is to live one's life, in particular how to make critical life-decisions" (Feinberg, 1986: 54). The domain of personal sovereignty thus extends beyond decisions affecting the body, to decisions about how one should live one's life. This domain will also include various trivial decisions, such as choosing what one should wear, the music one listens to, or even whether or not to vacuum the carpet. The boundary of personal sovereignty does not only include decisions that significantly affect the individual, but demands that individuals are the ultimate authority over *all* decisions important or trivial, about how they lead their lives.

Consequently, since an individual's choices will only have authority if they fall within the province of the personal domain the position of absolutism should be redrawn so that:

*Exercisable free choice has ethical priority and is protected by maximal respect for individual choices, **within the personal domain**, on the condition that the interests of other individuals are not harmed\**

### **5.3 SLAVERY CONTRACTS**

A further constraint that is placed on maximal respect for individual choices is a restriction on choices that forgo all or some future opportunities to exercise free choice. The typical example used to illustrate the abdication of all future opportunities for exercisable free choice is that of voluntary slavery. In such a scenario the individual makes a decision to relinquish all future exercisable free choice by becoming a permanent slave to another individual. All of the individual's actions will be determined by their future 'owner'.

It has been denied that such a choice should be respected for two separate reasons, specifically that slavery contracts are 1. self-contradictory, and 2. that it is unlikely that a person could freely choose to become a slave. First, the absolutist argues that a restriction should be placed on making such choices because such choices eliminate all future choices. As I will show, this argument has been rejected by absolutists. In the second place they have argued that choices which diminish the exercise of future choice should be prohibited in order to avoid the risk that an individual chooses enslavement when she lacks AC.

The first, and perhaps most famous of arguments used to explicate the wrongness of abdicating all future exercisable free choice, is that such a choice is self-contradictory. Mill attempts to argue the total surrender of free choice autonomy should not be respected because it is at odds with the value attributed to maximal respect for individual choices. Mill states that:

...by selling himself for a slave, he abdicates his liberty; he forgoes any future use of it beyond that single act. He therefore defeats, in his own case, the very purpose which is the justification of allowing him to dispose of himself (Mill, 2008: 114).

This situation, Mill suggests, is self-contradictory; one cannot make a free choice – and acknowledge its value – and thereby renounce all future free choices. Indeed, since the would-be voluntary slave must value his free choice in his demand that his choice to be a slave is respected then if he appreciates its value he cannot abjure his future opportunities for exercisable free choice. The Millian absolutist thus argues that we should restrict persons from becoming slaves in order to preserve their future

opportunities to exercise their free choices, something which would-be slaves implicitly value when making their initial choice to enter into slavery. It is thus: "...logically impossible...to contract to give up all [future exercisable free choice] since such a contract would deprive the person of the ability to make any agreements at all" (Assister, 1988: 59).

However, this particular line of argument is implausible since there is nothing in the concept of autonomy (as a capacity) that would preclude a person from autonomously choosing to become a slave (Dworkin, 1988: 129). In line with absolutism about respecting individual free choices, we should concede that the would-be slave is making an autonomous choice: "...albeit an unreasonable one by our standards" (Feinberg, 1986: 69). Indeed it could remain the case that even though the individual values her exercisable freedom of choice, there are other things that she finds more valuable. For instance: "[e]ither the would-be slave finds the prospect of slavery intrinsically appealing or he is willing to endure it for the sake of other benefits to be conferred by the owner as contractual 'consideration'" (Feinberg, 1986: 73). An individual could thus relinquish her autonomy – despite valuing it – in order to benefit from a circumstance that she values more, such as being in a condition of happiness. (Indeed, this was shown with the case of Fred in section 5.1 where Fred decided to sell his kidneys for financial gain in order to prevent his family from perishing)

Since the free choice to become a slave is not self-contradictory, the contention that slavery contracts should not be respected must be defended on other grounds. Rather than claiming that such choices are self-contradictory it has instead been argued that it

is unlikely that anyone could freely choose to become a slave because it is likely that the individual's AC is undermined. It is posited that: "[a]nybody who would agree to become a slave...must be in some way distracted, misinformed, impetuous, weak-willed, self-destructive, or so forth" (Dworkin, 1988: 126). It is thus doubted that anyone can in fact freely choose to become enslaved – in order for someone to choose this option she *must* of necessity be coerced or AC is absent.

Moreover, even if it this is not the case, the free choice to become a slave should be prohibited just in case she is not freely choosing it. This is because the risks of someone nonautonomously choosing to become a slave are very high. For this reason slavery contracts should be prohibited in order to avoid the risk of individuals non-autonomously making this choice:

The risks are so great that the possibility of mistake must be reduced to a minimum. It is by no means impossible for a given slavery agreement to be voluntary, but the grounds for suspicion are so powerful that the testing would have to be thorough, time-consuming and expensive...as to be impractical...the state might be justified simply in presuming nonvoluntariness, conclusively in every case as the least risky course (Feinberg, 1986: 79).

Since it is unlikely that anyone would freely choose to enter slavery, and because the risks associated with nonautonomously choosing slavery are so high (when the loss of exercisable free choice is recognised to be a great loss), it is argued that it is safer to ban the practice. Indeed, it is claimed that even if 'one hundred' people are denied permission to become slaves this is good since if it were to be allowed many people, who do not autonomously choose to become enslaved, will be wrongly permitted (Feinberg, 1986: 79-80).

The worry that certain contracts will be chosen by people who are unable to resist the option (and therefore do not choose freely) extends beyond the case of slavery contracts. Indeed many have argued that in other areas of life: "...that what looks like a free agreement is in reality often coerced, because the person entering it had no real alternatives" (Phillips, 2008: 102). For example, it has been objected that women can never freely choose to become prostitutes because the choice to become a prostitute might be the prostitute's only option. The option therefore cannot be resisted: "...it is a job that women – particularly women doubly disadvantaged by poverty and racism – engage in only under duress or when no other possible option appears to present itself" (Overall, 1992: 711). It has similarly been argued that an individual can be coerced with monetary offers. For example, when surrogate's are offered monetary compensation for their services, it: "...may be difficult for a person of little financial means to refuse and would, in that case, be coercive" (Wertheimer, 2000: 224). There has been particular concern with the coercive nature of 'surrogacy hostels' in India (Pande, 2010: 971). Surrogacy hostels recruit "...poor, rural, uneducated Indian women into the perfect mother-workers for national and international clients" (Pande, 2010: 970). Often third world women are seen to be coerced into becoming surrogates for rich western women because they desperately need money to provide for their own children. Pande notes the case of Regina, a forty-two-year-old surrogate desperately in need of money to secure a dowry in order that her daughter is seen as marriage material. Regina states:

I came to the clinic when my daughter was ill. The nurse is from my village, and she has seen the state of my daughter. She knows I am old but she told me if I want to be a surrogate, she would try to get me in. I was not agreeing in the beginning; I was too scared. But she said, 'How else will you get that mad daughter of yours married?' (Pande, 2010: 976)

In Regina's case the prospect of earning money – in addition to the Nurse's manipulative remark that paid surrogacy is Regina's only option if she wants her daughter to be married - makes the contract irresistible.

Hence, in addition to the concern that it is unlikely that an individual could freely choose to enter slavery it has also been claimed that it is unlikely that an individual could freely choose to become a prostitute or a commercial surrogate. Nonetheless, the absolutist tends not to place a restriction on choices that may be chosen out of desperate circumstances aside from that of slavery.

As noted in section 5.2, the domain of personal sovereignty allows that individuals have a privileged *right* to freely choose what to do with their lives (Savulescu, 2003). On this view it is held that the individual is the sovereign authority over her 'bodily domain' and may freely choose what happens *to* and what she does *with* her body even if such behaviour is detrimental to her overall well-being: when such choices are autonomous they *morally ought never to be overridden* (Faden and Beauchamp, 1986: 19). Since the individual owns her body it is claimed that freely given consent to the use of that body is sufficient for rendering that use ethical (Feinberg, 1986: 56).

However, the assumption that in order to prevent exploitation one need only freely offer consent has been convincingly argued to be false. As Widdows notes, in employment law workers are not allowed to sign contracts for employment that will damage their health or well-being, *even if* they freely choose to do so. This is because unsafe working conditions and low wages exploit the desperate need of some workers to make a living.

Restrictions are thus placed upon what the worker can consent to because she may be in a desperate position open to abuse by her employer (Widdows, 2009: 9). Note that these restrictions apply even if particular employers have no history of exploiting their workers. What is significant about these laws is the *chance* that workers will be exploited although they might freely consent to work under such circumstances.

Nonetheless, despite the controversy surrounding whether free consent cancels out the exploitative nature of certain practices, it is more commonly argued by absolutists that the free choice to become a prostitute or a surrogate mother should be left to the discretion of the woman: so long as she consents the choice is ethical *even if* it is thought that she is being exploited. For this reason it is more accurate to characterise the position of absolutism as only placing a restriction on the choice to become a slave whilst individuals should be free to make other choices that are contested as being equally vulnerable to coercion and thereby not deserving of respect. The position of absolutism should be modified thusly:

*Exercisable free choice has ethical priority and is protected by maximal respect for individual choices within the personal domain, on the condition that the interests of other individuals are not harmed\* **and that the choice does not inhibit all future opportunities for exercisable free choice.***

#### **5.4 CONCLUDING REMARKS**

In this chapter I have presented the position of absolutism. Although absolutism can be broadly characterised as maximal respect for individual exercisable free choice I have

shed light on some of the restrictions that an absolutist might consistently impose on their theory. This has included the adoption of the harm principle (5.1), an analysis of the domain of personal sovereignty in which it was shown that absolute respect for exercisable free choice only applies to those choices that are self-regarding (5.2). Finally it was shown that the absolutist places a restriction on respect for exercisable free choice, banning slavery contracts due to a concern that such contracts are unlikely to be freely consented to.

Finally, I argued that absolutism holds the following view:

*Exercisable free choice has ethical priority and is protected by maximal respect for individual choices within the personal domain, on the condition that the interests of other individuals are not harmed\* and that the choice does not inhibit all future opportunities for exercisable free choice.*

In the next chapter I will critique the thesis of absolutism as characterised above both in terms of the possible instrumental (section 6.2) and intrinsic (section 6.3) value of free choice. Since Chapter 6 will show that absolutism cannot be ethically justified it provides a strong basis for rejecting the prioritisation of informed consent procedures over the duty of care in medical practice.

## **CHAPTER 6: AGAINST ABSOLUTISM**

In this chapter I present a novel argument against the thesis of absolutism as an ethical guarantor. My thought experiment of a possible absolutist world in which respect for individual free choice is maximised (section 6.1) will be used to show that various claimed instrumental and intrinsic goods of free choice are poorly protected by the adoption of absolutism. In section 6.2 I argue against two accounts of the instrumental value of free choice, specifically that it is ethically important to respect free choice since free choice likely to get the individual what she wants (sections 6.2.1 and 6.2.2) and secondly that respect for exercisable free choice is therapeutically beneficial to the individual (section 6.2.3 and 6.2.4). I conclude that neither of these instrumental goods are well protected in the closest possible absolutist world and thereby reject them as a justification for prioritising free choice above all other ethical concerns. Finally, in section 6.3 I suggest that the claim that maximal respect for free choice is objectively valuable is contentious given that the exercise of free choice can lead to a decline in well-being. On the basis of these arguments I thereby reject the current standard in medical ethics of prioritising of informed consent procedures over the duty of care.

### ***6.1 A TEST FOR ABSOLUTISM***

I propose that a thought-experiment can be used to highlight the inadequacy of absolutism as an ethical guarantor when free choice comes into conflict with other ethical goods. Further still I will show that the ethical goods that the absolutist position

claims to promote are poorly protected by absolutism and are sometimes better protected by overriding or disrespecting an individual's exercisable free choice.

In this thought-experiment, I consider a set of possible worlds in which ethics is governed by absolutism. I shall refer to this set of possible absolutist worlds as PAW. Within the set of PAW there will be some worlds in which all of the absolutist values are maximised (in this world absolutism about respect for free choice will be true since all of the values it purports to respect will be met). There will also be some possible worlds in which none of the absolutist values are met (i.e. although absolutism is upheld, no one living in this world has AC). Or for instance, there may be some possible world in which the continued existence of the world depends on the violation of free choice. In this world absolutism would be false in this absurd situation since an absolutist might reasonably maintain that free choice could be violated in order to save the world.

However, since there are many possible absolutist worlds, that have many different outcomes with regard to the goods promoted by absolutism, my interest in exposing the flaws of absolutism does not lie with taking into account the set of PAW. Instead, I will be considering PAW\*: the closest possible world in which there is maximal respect for exercisable individual free choice.

Within PAW\* individual free choice will be maximally respected in accordance with the position of absolutism presented in chapter 5 and the definition of exercisable free

choice presented in chapters 3 and 4.<sup>38</sup> The position of absolutism draws upon this theory of exercisable free choice:

*Exercisable free choice has ethical priority and is protected by maximal respect for individual choices within the personal domain, on the condition that the interests of other individuals are not harmed\* and that the choice does not inhibit all future opportunities for exercisable free choice.*

I take it that PAW\* will be considered by the absolutist to be the ethically best model for the actual world. In subsequent sections I will present an exposition of the instrumental and intrinsic values claimed by absolutists to be protected by their thesis. I use PAW\* to assess their claims and expose their flaws.

## **6.2 THE INSTRUMENTAL VALUE OF FREE CHOICE**

It has been argued that respect for free choice is valuable because it is the best means to attaining a number of goods.<sup>39</sup> Since instrumental goods are only valuable because they are means to further attaining a separate good their value is conditional and so will

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<sup>38</sup> There it was defined that an individual is able to exercise free choice when she has (1) Substantive AC , that (2) there are no external non-judicial constraints preventing her from acting on her choices, that (3) There are no judicial constraints preventing her from acting on her choice (de facto liberty) OR that (4) She is judicially permitted to exercise her choice (de jure liberty).

<sup>39</sup> My analysis is restricted to the instrumental value free choice might have in medical decision making. For this reason, common explanations for the instrumental value of freedom, such as its conduciveness to Truth and Diversity, will not be explored. Mill has argued that freedom is instrumentally valuable since it provides a means for ascertaining the truth: "First: the opinion which it is attempted to suppress by authority may possibly be true. Those who desire to suppress it, of course deny its truth; but they are not infallible. They have no authority to decide the question for all mankind, and exclude every other opinion, because they are sure that it is false, is to assume that *their* certainty is the same thing as *absolute* certainty" (Mill, 2008: 22). A further instrumental good of freedom is thought to be its role in the development of a diverse society: "The despotism of custom is everywhere the standing hindrance to human advancement, being in unceasing antagonism to that disposition to aim at something better than customary, which is called, according to circumstances, the spirit of liberty, or that of progress or improvement." (Mill, 2008: 78). Since neither of these assessments explains why freedom might be instrumentally valuable in medical decision making contexts, they will be left aside in this chapter.

depend upon whether or not they succeed in securing the goods they are alleged to attain.

### ***6.2.1 Epistemic Privilege and the Problem of Communication***

In defence of absolutism it has been argued that patient free choice is valuable because it is likely to guarantee that the patient will get what she wants. It is claimed that the individual has a special access to her own desires and values – that she is epistemically privileged with regard to what she wants. Freely made decisions are thus claimed to be more likely to be compatible with what the patient desires because patients have a privileged access to what they would like, or what would contribute to the elements of their health they judge to be most important. Tännsjö, for example, argues that we should respect the autonomous medical choices of patients because they have a special expertise when it comes to their own well-being (i.e. a privileged epistemological position) (Tännsjö, 1999: 16). It is thus claimed that individuals are best equipped for making choices that will correspond with what they want. However, if the epistemic argument can be undermined (as I intend to show) then the instrumental value of free choice as a guarantor of ‘getting what one wants’ will also be undermined.

Scanlon offers a clear example in which the assumption of epistemic privilege rings true. Indeed, the instrumental value of free choice becomes apparent when considering practical choices such as what to order from the menu in a restaurant. The reason why a variety of options are available on the menu and why the selection of a meal is left to the individual is the presupposition that the ‘customer knows best.’ As Scanlon notes: “[t]he

most obvious reason why choice has value for me in this situation is simply instrumental: "I would like what appears on my plate to conform to my preferences at the time it appears, and I believe that if what appears then is made to depend on my response when faced with the menu then the result is likely to coincide with what I want" (Scanlon, 1986: 178). It is thus assumed that if the individual exercises her free choice in the selection of her meal she is more likely to enjoy it since she has an epistemic advantage over third parties concerning her gastronomic tastes.

However, there may be occasions in which another person is better able to choose an option which will satisfy my preferences. For instance, if I have never before experienced Indian cuisine then it would be sensible to ask the waiter for his recommendations. Indeed, since I do not know what my preferences are in this situation I am more likely to enjoy my meal if I seek the advice of others. In cases such as these I have no epistemic advantage.

Tännsjö admits that one might be suspicious of the epistemic advantage of the patient when making medical decisions. Indeed, he asks: "Does not the doctor know better than the patient about the medical status of the patient?" (Tännsjö, 1999: 16). However, for Tännsjö this sort of expertise is minimal in the sense that it can be easily communicated to the patient: "...this is a kind of knowledge that the doctor should be able to communicate to the patient, in all relevant respects" (Tännsjö, 1999: 16). However, Tännsjö's claim that expert information can be successfully communicated to the individual can be disproved. Indeed it has been strongly argued that the issue of communication in the practice of informed consent cannot be easily overcome.

Manson and O'Neill have convincingly argued that the theory of communication that underlies the doctrine of informed consent does not succeed in guaranteeing that medical information is successfully passed on to the patient who is at an epistemic disadvantage.<sup>40</sup> Manson and O'Neill evaluate the communicative demands of informed consent in terms of the conduit-container model of communication, conceptualising the contemporary English use of the term 'information' as: "...that which *is* conveyed in the process of informing," (Manson and O'Neill, 2007: 35) and viewing: "...communication as the [metaphorical] *conveyance* or *transfer* of something – of meaning; ideas; information, or most generally of content." (Manson and O'Neill, 2007: 36). These metaphors represent information as something which can be possessed and transferred between people. Informed consent is thus presented as being 'entrenched' with metaphorical assumptions that information can be possessed and transferred.<sup>41</sup>

In view of these deep-rooted metaphors regarding information, Manson and O'Neill argue that the conduit-container model cannot ensure that informed consent is successful, since the mere 'transfer' of information does not guarantee that communication will be successful. As they note: "[d]isclosure by itself may not reach its intended audience, so may fail to communicate what is proposed, or which commitments are offered; decision making by itself may fail to communicate whether consent is given or refused or which commitments are assumed in consenting." (Manson and O'Neill, 2007: 184) This is clearly illustrated with an example:

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<sup>40</sup> The following discussion of Manson and O'Neill's claims about informed consent and communication is adapted from my paper (Bullock, 2010: 535-540).

<sup>41</sup> Further argument for the intimate connection between informed consent and the conduit-container model of communication is not offered, although Manson and O'Neill regard their interpretation to be accurate.

...suppose Tom arrives at work and asks his colleague Sue, 'Have you seen Jane?', and Sue replies 'Oh, she went to the bank' ...By itself, the *sentence* 'Oh, she went to the bank' could mean a great many things. The pronoun 'she' could pick out any woman. The tensed construction 'went' does not, by itself, inform Tom *when* Jane (if it is she) went to the bank (last week? A year ago?) (Manson and O'Neill, 2007: 39)

By relying on the premise that 'ought implies can' Manson and O'Neill claim that the conduit container model of communication must be rejected, instead offering a revised model of communication.

An optimist like Tännsjö might be persuaded by Manson and O'Neill's alternative theory of communication which promises the successful transfer of information. On their 'agency' model successful communicative transactions will:

...succeed only where participants are sensitive to one another as agents with their own cognitive and practical commitments, and assume one another's adherence to a range of communicative, epistemic and ethical norms (Manson and O'Neill, 2007: 66).

They offer multiple features and norms which govern their agential account in order that communicative transactions are successful. The features required for effective communication between doctor and patient will include (1) a shared language; (2) a shared background knowledge about the world; (3) inferential competence on the part of both parties; and (4) knowledge of each others' commitments and competencies. (Manson and O'Neill, 2007: 56). Although Manson and O'Neill do not offer an exhaustive list of the norms governing communication, they do assert that successful communication requires that both parties (i) are epistemically responsible, (ii) are

relevant, (iii) are intelligible, (iv) aim for accuracy, (v) do not lie, deceive or manipulate, (vi) do not mislead, (vii) provide relevant qualifications and caveats to the information they convey (Manson and O'Neill, 2007: 59).

Returning to their example of Tom and Sue we can see how the agential model succeeds where the conduit-container model of communication failed. Rather than simply conveying and depositing packets of information:

Sue...can draw upon her knowledge of the content of the utterance, and her assumptions about which practical and cognitive commitments are likely to motivate Tom to ask his particular question ('Tom doesn't know where Jane is'; 'Tom wants to know where Jane is') (Manson and O'Neill, 2007: 40).

Sue can successfully communicate to Tom the whereabouts of Jane on the agential model given the practical and cognitive commitments she correctly assumes Tom has. In contrast to the conduit-container model which views information as packets which can be deposited, the agency model guarantees successful communication because it relies upon the practical and cognitive assumptions of the interlocutors and adheres to a set of epistemic and cognitive norms.

However, even though they have the correct motivation for developing an alternative account of communication to underlie informed consent procedures, the agential account that they develop is not itself unproblematic. In order to see why this is the case it is useful to take an example:

Ms. A has recently been suffering severe pain in her left foot. The tissue has turned black and has started to produce foul-smelling pus. After a thorough examination of her foot Dr. X confirms that her patient is suffering from wet gangrene, which needs to be treated by amputation in order to prevent septic shock. However, before this procedure can commence Dr. X is legally obliged to seek the informed consent of her patient. Important for this example, we must note that Ms. A has watched several medical dramas in which such a procedure led to the death of the patient. For this reason, and unbeknown to the doctor, Ms. A has formed the belief that such treatment will severely diminish her chances of survival; she has taken the plotlines of several medical dramas as evidence that amputation leads to death and on the basis of this has refused treatment.

In order for informed consent to be reached on the conduit-container model, Dr. X would be obliged to inform her patient of the procedure and the risks it might entail, documenting the patient's consent or refusal. On this model the Doctor is surprised to discover that her patient refuses to consent to the treatment despite conveying all of the relevant 'packets' of information to her. The conduit-container model fails because it does not take into consideration the cognitive and practical commitments of the patient - including false beliefs about the reliability of treatment - making it an inadequate communicative model for obtaining explicit and specific informed consent.

In contrast, according to the agential model of communication, the communicative transaction between Dr. X and Ms. A would be successful once Ms. A's false belief about the riskiness of the treatment was taken into consideration. Only once this assumption has been made explicit could Dr. X become aware of her patient's belief in the riskiness of the treatment and attempt to persuade her that her belief is mistaken. When such features of communication are made known consent to or refusal of medical treatment on the part of the patient could be achieved.

However, the agential account of communication does not make the process of obtaining informed consent any less demanding. Rather, the norms, assumptions and commitments that need to be shared for successful communication are simply rendered explicit. The agential model of communication thus does not obviously make the obtaining of informed consent more feasible, but simply demands that the epistemic and cognitive norms and assumptions are shared. This is made clear in cases like that of Ms. A and Dr. X in which the norms and features of successful communication should not be assumed to be shared on the basis that the patient has a mistaken belief. Indeed, in the example Dr. X is unaware of Ms. A's mistaken belief in the likely fatality of the treatment, and likewise Ms. A is unaware of the mistakenness of her belief. In such situations the practical and cognitive assumptions of each party would need to be investigated and made known in order that communication, and thereby informed consent, is successful.

It might be suggested that Manson and O'Neill do not treat the features and norms of communication as a list that needs to be explicitly checked, but rather as an implicit set of shared norms; so long as these features and norms are shared communication will be easy. This is correct insofar as the features and norms are shared. In medical contexts similar to that of Dr. X and Ms. A, however, these features must be *explicitly* checked in order for communication to be successful, since the successful acquisition of informed consent will depend upon uncovering mistaken assumptions. Indeed, Dr. X and Ms. A do not have shared assumptions about the world and the riskiness of the treatment. The only way in which persons who do not have shared backgrounds and assumptions can communicate successfully is if the differences in their beliefs are made explicit. The agential theory of communication will thus be fairly demanding of both Dr. X and Ms. A

to ensure that she can consent to the treatment. Moreover, the demands of the agential theory of communication will amplify when the assumptions and norms of the doctor and patient increasingly diverge.

Although Manson and O'Neill are certainly correct to attempt to revise the conduit-container model of communication, the benefit of their account is not that it simplifies the consent process, but rather that it renders the demanding features of communication explicit in medical situations where shared background knowledge about the world, inferential competence and knowledge of each others' competencies and cognitive commitments cannot be easily assumed. It is therefore obtuse to presuppose that the problems of the patient's lack of epistemic privilege can be overcome with adequate communication – in fact successful communication would be an extremely time consuming and overly burdensome process.

### ***6.2.2 The Absence of Epistemic Privilege in PAW\****

I have shown that the claim that individuals have an epistemic privilege with regard to their preferences - and so that the protection of free choice is instrumental to ensuring that their preferences are satisfied - does not always hold true. Firstly, there are many cases in which an individual does not know her preferences. Secondly, I have argued that the communication of information that is needed for the individual to make a decision based upon her preferences, specifically with regard to informed consent in medical practice, is unlikely to be successful.

As outlined, PAW\* will uphold the absolutist thesis that respect for free choice should be maximised. PAW\* will thus be governed by the ethical theory that:

*Exercisable free choice has ethical priority and is protected by maximal respect for individual choices within the personal domain, on the condition that the interests of other individuals are not harmed\* and that the choice does not inhibit all future opportunities for exercisable free choice.*

This means that the individual will be required to make choices in situations where she has no epistemic privileges with regard to her preferences. Significantly, such choices are unlikely to protect her best interests, and if they do so, this will be a fluke.

To be sure, there will be some occasions where free choice will satisfy the individual's preferences. This will be in cases where the individual has ready access to her preferences and the relevant information about the options within their choice-set, such as in Scanlon's restaurant example. However, where epistemic access and information are unavailable to individuals in PAW\* individuals will have difficulty satisfying their preferences. Firstly, the maximal respect for free choice in PAW\* means that no-one can interfere with what they regard to be a risky or bad decision. A person thus cannot intervene with an option choice that they believe will fail to satisfy the individual's preferences. To make this clear, let us return to the Indian restaurant and imagine an individual who dislikes spicy food but who orders a Vindaloo. In PAW\* other persons may not interfere with her choice. This means that in this case and in similar circumstances there will be individuals in PAW\* who fail to satisfy their preferences by exercising their free choice.

Secondly, in situations where individuals seek the expertise of others in order to help them make a decision there may be difficulty in communicating the relevant information. Where communication is unsuccessful the individual is likely to fail to make a choice that will satisfy her preferences. This is particularly problematic in medical practice where the expertise in diagnosing illness and prescribing treatment involves complex information that may be difficult to communicate to the patient. Individuals who do not succeed in obtaining correct information regarding their options and how they relate to their preferences will fail to protect their best interests. This will be significantly worse in PAW\* when individuals are *required* to make all of the decisions without interference.

The absolutist has claimed that free choice is instrumentally valuable because individuals have an epistemic privilege with regard to their preferences and so can make choices which satisfy them. The first conclusion that can be drawn from the PAW\* thought-experiment is that the maximal respect for free choice is not always instrumental to satisfying individual preferences. This is because (1) individuals do not always have an epistemic privilege with regard to their preferences, (2) expert information about the options within a choice-set cannot always be successfully communicated. I have thus shown that if the satisfaction of individual preferences is valuable to the absolutist, then in light of PAW\* they have a reason for rejecting their position.

### **6.2.3 Therapeutic Gains and Losses**

A second argument for the instrumental value of free choice is that it is therapeutically beneficial to allow individuals to make their own decisions. The notion that individual free choice ought to be respected can thus be defended on utilitarian grounds. John Stuart Mill famously defended a principle of respect for individual choice as a means of maximising utility. Mill argued that individual free choice guarantees an increase in utility since the individual's 'choice of pleasure' rests with her own judgement (Mill, 2008: 112). Given the supposed truth of Utilitarianism and the thesis that individual choice is essential for utility Mill argues that: "...extensive respect for individual liberty is morally required" (O'Neill, 2002: 32). Millian arguments for the importance of protecting individual choice are thus defended on the presumed notion that such protection allows for maximal utility.

The claim that free choice guarantees an increase in utility also has support from medical ethics, economic and psychological theory<sup>42</sup>. For instance, research and theory in microeconomics has posited that the provision of free choice: "...is necessarily advantageous because it allows for utility maximisation" (Botti and Iyengar, 2006: 25). Indeed, it is supposed that individual free choice: "...can never reduce well-being, because it enables consumers to engage in preference matching without necessarily burdening their cognitive system" (Botti and Iyengar, 2006: 26). Free choice is thus claimed to be instrumental to promoting utility and so instrumentally valuable.

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<sup>42</sup> Although in other studies it has been suggested that the opportunity to select from too many options can lead to adverse consequences such as decreased motivation to make a choice or to make any choice at all (Scheibehenne et. al, 2010)

The notion that individual choice is an instrumental means of attaining utility is also defended in psychological theory. It is claimed that the positive utility effects of free choice include increased motivation and cognitive performance, because choice allows people to feel in control of their own fate: "...thus improving psychological and physical condition. People given choices have been found to experience increased life satisfaction and health status, whereas the absence or removal of choice makes them helpless and hopeless" (Botti and Iyengar, 2006: 25). The protection of free choice is thus claimed to be instrumental to promoting well-being because the actual process of freely making a choice is itself enjoyable.

Within medical practice it has been claimed that free choice is instrumentally valuable to medical decision making since it improves the patient's well-being. Firstly, being in charge of one's medical decision making is argued to speed recovery. Schneider has argued that there is some evidence that: "...patients who control their treatment will more surely be quickly restored to health" (Schneider, 1998: 18). There are also suggestions that patient control: "...may enhance health by strengthening the immune system" (Schneider, 1998: 19). There is thus some evidence that making free choices within medical ethics promotes utility by directly aiding recovery.

However, there is strong counter-evidence that free choices do not always correlate with these therapeutic benefits. Indeed it is bizarre to suppose that free choice guarantees a promotion in utility when the absolutist thesis is premised on the claim that *all* free choices should be respected, *regardless* as to whether they are imprudent or harmful to the individual. As Scanlon claims, the outcome of free choice and the promotion of

welfare do not necessarily correlate: “[i]n fact, the demand to make outcomes depend on people’s choice and the demand to promote their welfare are quite independent, and they can often pull in opposite directions” (Scanlon, 1986: 189).

Cases in which free choices lead to a decline in well-being can be elucidated with examples of sick and tragic choices made within medical practice. Firstly, free choices might be inherently undesirable because the patient is sick - some patients may thus find decision making undesirable given their illness. Indeed a psychological study has shown that the desirability of medical decision making is negatively correlated with the severity of the illness: “...the more severe the illness, the lower the desire to make personal decisions” (Botti and Iyengar, 2006: 32). Thus, although sick patients may meet all the criteria for exercising free choice (see section 3.2) and so have their choices worthy of respect, they may suffer a decline in well-being by making their own choices about their medical treatment.

Moreover, even if a patient finds making her treatment choice desirable, the fact that she does so does not guarantee that she will receive any therapeutic benefit. Indeed, the direct therapeutic benefits or losses associated with making a choice are related to the amount of information an individual has with regard to her options. As presented in sections 4.2.1-2., successfully communicating relevant information is near impossible. Indeed, Schneider argues that even if a patient desires to make free choices regarding her treatment this does not mean that she will benefit from making her own decisions since the information needed to match her preferences to her options will be absent. Her ability to make a therapeutically beneficial decision will thus be: “...constrained by

doctors' limited capacity to convey information and by patients' limited capacity to understand and analyse it" (Schneider, 1998: 151). The requirement that individuals make free choices will often be psychologically distressing. The pressure to make a choice when one is uncertain of one's preferences and/or does not have the relevant information to make a decision one is happy with will be burdensome. Thus: "...the very provision of choice, which is seemingly desirable and beneficial, can become paralyzing and debilitating" (Botti and Iyengar, 2006: 24). The Millian claim that free choice is instrumentally valuable in the promotion of utility is not a necessary connection.

Further still, there are cases in which the individual is appropriately informed but in which she still suffers a decline in utility by exercising her free choice. This can be the case when patients are faced with inherently tragic choices. In a study by Botti et. al. (2009), empirical evidence is provided that supports the theory that tragic choices can lead to a decline in well being. In the study Botti et. al. focus on cases of withdrawing life-sustaining treatment from a critically ill infant. The options available within the choice-set included (1) the withdrawal of treatment resulting in death or (2) the continuation of treatment with only a slightly higher chance of survival in a severely impaired neurological state. These choices available to the parents can be recognised as tragic since both of the options available are highly undesirable.

In the study, groups of parents were given different decision making methods. The first group, based in the USA, were given the freedom to make the decision with regard to the cessation or continuation of their child's treatment. The second group, based in France, were not given the choice. Instead, the decision was made by the medical practitioner.

In subsequent interviews with the parents after to the final treatment outcome it was discovered that the American parents, who exercised their free choice in making their child's treatment decision felt more negative emotion regarding the outcome than the French parents, for whom the decision was made by their neonatologist. Interestingly: "...most of the French parents did not express the same level of grief and distress as their American counterparts" (Botti et. al., 2009: 341). This body of empirical data evinces the conclusion that being forced to make one's own treatment decisions can lead to a decline in emotional and psychological well-being if the choice made is highly undesirable.<sup>43</sup>

#### ***6.2.4 Therapeutic Decline and the Consequences for PAW\****

There is a great deal of support for the theory that free choice promotes well-being. Indeed, philosophers, economists and psychologists have all propounded the position that respect for exercisable free choice is instrumentally valuable. However, despite Millian arguments for the maximisation of free choice, I have argued in the above that there is no necessary connection between free choice and the promotion of welfare. First, in some situations making one's own decisions may be incredibly undesirable. Within medical practice these situations may be fairly common given that the sick may find making their own medical decisions an unwanted burden. Second, even when

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<sup>43</sup> The guilt felt by the American parents is likely to be connected with the responsibility they have to decide the outcome of their child's life. This is directly connected to the legal justification for informed consent procedures (1.3.3): under the doctrine of informed consent the doctor is no longer responsible for determining the treatment of her patient, and thereby is not liable to be sued for making that decision. The responsibility for choosing medical treatment thus falls upon the patient or proxy: given this responsibility it is therefore unsurprising that an individual will have feelings associated with that responsibility, such as regret, blameworthiness or guilt. These possible reactions mean that the provision of free choice does not guarantee therapeutic benefit. Note that whether or not the legal justification for informed consent should be rejected cannot be explored within this thesis. However, the correlation between protecting the doctor and the patient's (sometimes harmful) feelings of responsibility indicates that the legal justification should be reassessed in terms of its ethical standing.

individuals find free choice desirable, the lack of appropriate information and instances of tragic choices can possibly lead to a decline in utility.

Consequently those who are sick, poorly informed or faced with tragic choices in PAW\* will suffer a decline in utility because they will be *forced* and expected to make all of their decisions. I thus propose that if the protection of free choice is presented as instrumentally valuable because it promotes utility, then the absolutist will have to reject PAW\* since maximal respect for free choice will lead to a decline in utility.

### **6.3 THE INTRINSIC VALUE OF FREE CHOICE**

The possible instrumental value of free choice has been shown to be undermined by its conditional nature; it has been shown that in situations where individuals lack epistemic privileges and fail to gain therapeutic benefits from their free choices that there is no instrumental value to respecting individual free choice. Due to the relative nature of instrumental value some absolutists have thus defended free choice on the basis that it is intrinsically valuable. Unlike instrumental values, which are means to attaining some further value, intrinsic values are valuable in themselves. Thus, if free choice is intrinsically valuable this means that free choice is valuable *in itself*, not as a means to the attainment of some further good; free choice will be of value even if this leads to a decrease in welfare or to bad consequences.

### **6.3.1 Objective Desirability**

One argument for the intrinsic value of free choice proposes that it is objectively desirable that one chooses for oneself if one is capable of exercising free choice. The term 'objective desire' does not depend upon an individual's ascription of value to free choice: an individual's valuation of the desirability of choice would be the 'subjective' desirability of free choice.<sup>44</sup>

Scanlon supposes that the value of free choice can be explained in terms of subjective desirability, i.e. the value a particular individual ascribes to it:

...the value of the choice to a particular individual, taking into account the importance that individual attaches to having particular alternatives available, the difference that it makes to the individual which of these alternatives actually occurs, the importance which the individual attaches to having this be determined by his or her reactions, and the skill and discernment with which that individual will choose under the conditions in question (Scanlon, 1986: 182).

Having freedom of choice within a given situation might be interpreted as valuable because it is a situation which the individual finds desirable. Indeed, Berlin claims that the appeal of free choice lies in the desire that one's life and decisions depend upon oneself (Berlin, 2006: 43). Securing freedom of choice within medical practice has thus often been supposed to be of value because it satisfies the patient's desire to make her own decisions.

However, because subjective desirability is relative to the individual the explanation of the value of free choice in terms of subjective desirability is instrumental and so falls

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<sup>44</sup> I expand on the position of objective desirability in section 7.5

prey to some of the arguments raised against epistemic privilege (sections 6.2.1 and 6.2.2) and therapeutic benefit (sections 6.2.3 and 6.2.4). Thus the conditional nature of desire for making free choice means that it cannot be a justification for absolutism.

The supposition that free choice is desired by the individual has been shown in previous sections to be exaggerated. In medical contexts patients can reasonably desire that their free choice is restricted if they feel unable or too sick to make a free choice. The argument that free choice is valuable because it is subjectively desirable to the individual will thus be problematic for the absolutist trying to account for the value of maximising respect for free choice. Indeed, it could turn out that *no-one* subjectively desires having free choice. Quite simply, if the individual lacks the subjective desire to make free choices then the provision of free choice will lack value. If this were the case then free choice would lack any value, something which – I want to presuppose – the absolutist would like to deny.

Consequently, if absolutists want to account for the value of free choice in terms of its desirability they must do so in terms of its *objective* desirability. Objective desirability refers – fairly obscurely – to something that is desirable to the individual regardless of what she subjectively believes she desires in a given situation. It is defended on the grounds that it is desirable that one's life and decisions depend upon oneself even if such action leads to a decline in well-being (Berlin, 2006: 43). According to the absolutist free choice is objectively desirable in spite of whether the individual finds it subjectively desirable.

However, the claim that free choice is objectively desirable is controversial. Firstly, the elusive nature of 'objective desirability' renders this particular account of the value of free choice inconclusive. Indeed, it may be reasonably posited by opponents of absolutism that in some instances it is objectively *undesirable* to respect free choice. Given the arguments put forward in sections (6.2.1-6.2.4), it may reasonably be thought that it is objectively desirable to make decisions on the patient's behalf if they are sick, uninformed or faced with tragic choices. We therefore simply have a stand-off between those theorists that find the exercise of free choice objectively desirable and those who do not.

Secondly, as Dworkin notes, the claim that free choice is objectively desirable does not get so far as to justify the maximisation of free choice. Indeed, the supposition that more choice leads to an increase in value: "[f]or if choice has value just in virtue of being choice, then more of it must have more value" (Dworkin, 1988: 80) cannot be sustained. By drawing a comparison with other things we think of as intrinsically valuable, Dworkin correctly points out that the claim that more choice equals more value is false. For instance, if it is thought that having a child is intrinsically valuable it does not follow that having more children is necessarily better (Dworkin, 1988: 80). Thus, even if free choice is objectively desirable it does not follow that it should always be maximised, or that it is always objectively desirable.

Without further explanation, the claim that respect for free choice is objectively desirable thus fails to persuade that maximal respect for free choice is valuable. In terms of the elusive nature of objective desirability and the problematic that objective

desirability does not give us a justification for maximising respect for free choice, where free choice comes into conflict with other ethical values (as it does when informed consent procedures come into conflict with the duty of care) the purported value of free choice cannot be accounted for in terms of its objective desirability.

### **6.3.2 Absence of Objective Desirability and Consequences for PAW\***

Considerations of objective desirability have been inconclusive in explaining the value of free choice. Although the maximisation of free choice has been shown to fail to be justified by its objective desirability, the objective desirability of free choice is highly contentious – especially given its associations with therapeutic decline. We thus have a stand off between those who think that free choice is objectively desirable and those who think that it is not. However, when evaluating the value of free choice in terms of PAW\* we do not have a stand off. Since it has been shown that *even if* free choice is objectively desirable this does not justify its maximisation then PAW\* will not be of peak value. Indeed it could be plausibly claimed that it is *not* objectively desirable for patients in PAW\* to always make their own decisions. It remains unclear as to whether life in PAW\* would be valuable on the objective account.<sup>45</sup>

## **6.4 CONCLUDING REMARKS**

The purpose of this chapter has been to provide an objection to the position of absolutism as an ethical guarantor when the exercise of free choice comes into conflict

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<sup>45</sup> Moreover, I will develop an account of objective goods in section 7.5 in which I will show that other things seen as objectively good could come into conflict with the objective desirability of exercising free choice. An objective account of the value of free choice thus must contend with objective list theories which include the exercise of free choice as valuable, but does not reduce the account to it.

with other ethical goods, thereby undermining the prioritisation of informed consent procedures above the duty of care in medical treatment contexts. To this end I developed and applied a thought-experiment in which the instrumental and intrinsic goods that are claimed to be protected by an adoption of absolutism were shown to be poorly protected in the closest possible world in which there is maximal respect for individual free choice (PAW\*).

In sections 6.2.1 and 6.2.2 I used PAW\* in order to test the absolutist claim that maximal respect for free choice is valuable because it is likely to guarantee that the patient will get what she wants. There it was argued that free choice is not likely to guarantee that the patient will get what she wants because an individual is not always epistemically privileged with regard to the nature of her preferences. Furthermore I claimed that an individual cannot be fully informed, and therefore become epistemically privileged with regard to the decision that is most likely to get her what she wants, through a process of communication. This was shown to be problematic because an uninformed individual may be unable to understand how her options relate to her preferences. When this individual exercises her free choice she is unlikely to get what she wants.

Furthermore, in sections 6.2.3 and 6.2.4 I argued against the absolutist claim that it is therapeutically beneficial to allow individuals to make their own decisions since it is always possible to exercise one's free choice in a way that leads to a decline in one's welfare. Indeed, the promise of informed consent procedures in tandem with the harm\* principle is that individuals should be free to make risky, harmful and imprudent

decisions. It was thereby shown that the exercise of free choice can often lead to a decline in utility.

Finally I argued against the absolutist claim that exercising free choice is intrinsically valuable regardless as to whether it allows the patient to get what she wants (section 6.2.1) or benefits her therapeutically (section 6.2.3). This claim was assessed in terms of the objective desirability of free choice (section 6.3.1). I argued that this position is contentious since it has been shown that the exercise of free choice can lead to therapeutic decline. In conclusion, given that the ethical value of maximal respect for patient free choices cannot be explained in terms of the instrumental and intrinsic values considered here the onus is on the defender of the prioritisation of informed consent procedures to provide an alternative account. As it stands there is no ethical justification (aside from legal necessity [see section 1.2.3]) for prioritising informed consent above the duty of care.

## CHAPTER 7: PATIENT BEST INTERESTS

In the last chapter I objected to the absolutist's prioritisation of respect for exercisable for free choice above all other ethical considerations in cases where it was supposed that that respect for free choice was likely to enable the individual to get what she wants (section 6.2.1), benefit her therapeutically (section 6.2.3) or because it was objectively desirable (section 6.3.1). The fallout of this objection was that the prioritisation of informed consent procedures above the duty of care cannot be ethically justified.

In this chapter I address the claim that individual free choice should be respected because the individual is the best authority as to the nature of her best interests (section 7.1). In order to assess this claim I explore various theories of well-being that could be used as an account of best interests to see whether a patient's well-being is better protected under the doctrine of informed consent (i.e. maximal respect for her competent exercisable free choices) or under the duty of care.

Here I analyse and reject hedonic mental state accounts (section 7.2) and desire satisfaction accounts (section 7.3), finally defending an objective list account of well-being and patient best interests in section 7.5. Although I am unable to develop a complete account of objective well-being and patient best interests (nor is it feasible to do so here) my defence of an objective list account of well-being will highlight that an individual is not automatically the best authority for determining the medical decision that is in her best interests. For this reason, a defence of the prioritisation of the doctrine

of informed consent on the basis that the patient is an authority as to the nature of her best interests cannot be sustained.

However, within the context of this thesis I am unable to develop a full account of objective well-being that can be applied in medical practice. Nor is it plausible to provide an account of what medical decisions are in a patient's best interests in every instance in which it is an issue. The result of this analysis is to highlight that an individual is not automatically the best authority for determining the medical decision that is in her best interests, and therefore that the doctrine of informed consent is an unsuitable means for protecting patient well-being.

The content of this chapter has further implications. In Chapter 4 I defended a substantive account of AC. This account conceptualised AC as having a normative ability to make decisions in light of the True and the Good. Consequently, one of the factors governing whether an individual could exercise free choice was that she was able to make Good choices rather than Bad ones. As was argued then (section 4.3) the nature of the Good is compatible with a variety of ethical positions. This chapter, however, will argue that the Good that an individual must be receptive to in order to have AC, and thereby capable of exercising free choice, is objective.

### ***7.1 ABSOLUTISM AND THE SUBSTITUTED JUDGEMENT STANDARD***

The British Medical Association's handbook on medical ethics claims patient exercisable free choice ought to be respected because the patient is the best authority on the nature

of her best interests: “[w]hen patients are competent and have access to information, they are the best judge of what is in their interests and whether the expected benefits of a proposed treatment outweigh the burdens” (English, 2004: 108). The crucial caveat in this claim is that the patient must be *competent* in order for her to be the best judge of her best interests (chapter 2). When a patient is determined to be incompetent to make medical decisions an alternative method of medical decision making is used. As explained in section 2.5.1 the method that is standardly adopted is referred to as the ‘Substituted Judgement Standard’ (SJS). On this standard, substitute decision makers aim to protect the incompetent patient’s best interests by selecting the medical treatment options that the patient herself would have made, were she to be competent (Grisso and Appelbaum, 1998: 165). Presumably the motivation for SJS is that if the patient were competent then she would be best placed to make a decision that protects her best interests: when making a decision on behalf of an incompetent individual it is thought that her best interests are best protected by making a decision that she would probably have made. SJS thus goes hand in hand with absolutism about respect for patient exercisable free choice by assuming that the patient would have been the best judge of her best interests.

In order to determine whether absolutism and SJS are correct in assuming that the patient is an authority as to the nature of her best interests, it is instructive to assess competing accounts of individual well-being.<sup>46</sup>

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<sup>46</sup> I will be drawing upon Derek Parfit’s basic distinction between hedonic mental state accounts, desire satisfaction accounts and objective list accounts (Parfit, 1984: 493). I will only be assessing some of the main theories of well-being in order to indicate that patient’s are often not the best judges of the nature of their best interests and so we have good reason for adopting an objective list account of well-being, not that the objective list account of well-being is true.

In the following I will be defining the medical decision that is in the patient's 'best interests' as the one that is most likely to protect or improve the patient's overall well-being. Whilst I will be partly assessing the suitability of accounts of well-being in terms of whether they show that the patient is the best-judge of the medical option that is in her best interests to satisfy, I will also be assessing the accounts in terms of their own merits and failings to account for well-being.

## **7.2 THE HEDONIC MENTAL STATE THEORY**

The Hedonic Mental State account identifies the individual's well-being with a particular sort of experiential feeling: "...the hedonic level is characterised by the 'feel' of the situation" (Tännsjö, 2007: 81). Specifically, the hedonic mental state account measures individual well-being in terms of the individual's experienced pleasures and pains. According to the hedonist, individual well-being is constituted by: "[p]leasure for pleasure's sake...and nothing else is an end in any sense, except so far as it is a means to pleasure" (Bradley, 1988: 93). The individual's well-being is thus defined as the accruelement of pleasurable *feelings*: "[t]he hedonic level or state of the person is a characteristic of the total experience of this person at a certain time" (Tännsjö, 2007: 81). On this account it would be in the best interests of the patient that the outcome of her medical decision leads her to experience more pleasure than pain.<sup>47</sup>

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<sup>47</sup> The hedonic mental state account need not demand that it is in the patient's best interests to immediately experience more pleasure than pain as a consequence of her decision. The account leaves room for the idea of long-term and short-term pleasures and pains. On this account it is therefore possible for a patient to make a decision that causes her short-term pain, followed by long-term pleasure and for this to be in her best interests.

In the context of medical decision making, the hedonic mental state theory of well-being would interpret a patient's best interests in terms of medical decisions that are likely to lead to the experience of more pleasure than pain. A consequence of this position would be that a patient is best-placed to make a medical decision that protects her best interests just so long as the outcome of her decision is likely to cause her to experience more pleasure than pain. If the preceding is true then competent patient decision should be respected, and SJS utilised for the sake of protecting the best interests of the competent or incompetent patient.

Put in the context of medical decision making and the duty of care, the hedonic mental state theory is an unsuitable theory for determining what is in the patient's best interests. As I will show below, judging that the best medical decision is based on the amount of pleasure patient will consequently experience is in fact highly *impractical* and that it is neither a necessary nor sufficient account of patient well being. It is thus an inadequate model for assessing whether the medical decisions of competent patients are in their best interests and for making decisions on behalf of incompetent patients.

### **7.2.1 The Experience Machine**

The inadequacies of the hedonic mental state as an account of well-being are captured by Robert Nozick's thought-experiment of the experience machine. Nozick intends to bring out the intuition that there is more to well-being than maximising pleasant experiences by reflecting on our intuitions regarding false beliefs. Nozick asks us to consider:

...an experience machine that would give you any experience you desired. Superduper neuropsychologists could stimulate your brain so that you would think and feel you were writing a great novel, or making a friend, or reading an interesting book. All the time you would be floating in a tank, with electrodes attached to your brain...Would you plug in? *What else can matter to us, other than how our lives feel from the inside?* (Nozick, 1974: 42-3)

Nozick claims that we would not want to plug into the machine because there are things that we intuitively think contribute to our well-being besides the experience of pleasure. Firstly, Nozick suggests that: "...we want to *do* certain things, and not just have the experience of doing them" (Nozick, 1974: 43). He thus thinks there is value in carrying out certain actions by actively directing our own lives. A further reason offered for not plugging into the experience machine is that: "...we want to *be* a certain way, to be a certain sort of person. Someone floating in a tank is an indeterminate blob" (Nozick, 1974: 43). Not only do we want to direct our own lives, but we want to be the sort of person that directs our own lives. Thirdly, Nozick suggests that: "...plugging into an experience machine limits us to a man-made reality, to a world no deeper or more important than that which people can construct. There is no *actual* contact with any deeper reality" (Nozick, 1974: 43). We are thus supposed to conclude that we value certain things in addition to pleasant experiences and that this value can be found in wanting to *be* the sort of people who *direct* their own lives in contact with *reality*.

The fall out of this thought experiment is that we intuitively find the hedonic mental state theory an impoverished account of well-being. If it is correct that we want to do and be certain sorts of people in contact with reality in addition to having pleasurable experiences, then maximal pleasurable experience within the machine does not bring us

well-being. Consequently, it is possible for someone to sacrifice an experience of pleasure for the sake of something else that she intuitively considers to contribute to her well-being – for instance doing certain things and being certain sorts of people in contact with reality.

It has been objected that Nozick's claim that we would not plug into the machine is not true (Tännsjö, 2007: 93). Indeed, it seems perfectly *possible* for a person to want to plug into the machine, regardless of the other things that we consider to constitute well-being. Moreover, if, as the hedonist claims, the only constituent of the well-being is the experience of pleasure then our intuition that we would not plug into the machine is faulty – we might *think* that there are other good things aside from pleasurable feelings, but the hedonist would claim that this is simply mistaken.

However, to bite the bullet on this point is stubbornly unintuitive, and this is what Nozick's thought-experiment shows. As Brock notes, the important thing for this thought experiment is not that we all share the intuition that we would not want to plug into the machine. Rather, it points out that *even if* we would choose to plug into the experience machine despite its defects, we would still be failing to lead a good life. Thus, even if one was happy in the experience machine, or with leading a dull life, this would still be to: "...to get *less* from life or to have a less good life" (Brock, 1989: 40). There *are* things that we consider important to the good life that the hedonic mental state theory fails to account for such as feeling pleasure from true facts about the world. This renders it insufficient as an account of well-being.

These intuitions about our reluctance to plug into the machine are reflected in real world situations in which (a) we consider certain actions as being detrimental to our well-being despite being accompanied by pleasurable experiences, (b) when we consider certain actions as contributing to our well-being despite them not being accompanied by pleasurable experiences and (c) when pleasurable experiences accompany false beliefs.

Firstly, in the real world there are things that we find pleasure in, but which we consider as being detrimental to our well-being. Ross suggests that a prima facie advantage of the mental state account is that often our judgements of things that are in our best interests are in fact accompanied by pleasant feelings towards them (Ross, 2007: 80). However this is straightforwardly not *always* the case since pleasure can often arise in conjunction with something we would consider as being detrimental to our best interests. Many individuals, for instance, find smoking and eating foods high in saturated fat to be highly pleasurable but recognise that it is not in the best interests to do so because the inhalation of smoke and consumption of fatty foods is detrimental to their health. For this reason an account of well-being cannot be straightforwardly reduced to the experience of pleasure. There thus remains logical space for an individual to find something highly pleasurable that detracts from her well-being. Thus, even if something is pleasurable we may remain doubtful that it is sufficient for individual well-being (Ross, 2007: 83). The hedonist claim that 'wellbeing' and 'pleasure' are identical is false (Ross, 2007: 81-2).<sup>48</sup>

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<sup>48</sup> Throughout this section the objection could be raised that it is possible for a defender of the hedonic mental state account of well-being to draw a distinction between long-term and short-term pleasures. On this basis they could thereby explain why it is not in our best interests to eat fatty foods (despite the short-

Secondly, it is possible for an individual to consider certain actions as contributing to her well-being despite them not being accompanied by pleasurable experiences. In contradistinction to the previous case, imagine that the person who finds pleasure in eating fatty foods knows that it is in her best interests to eat more fruit and vegetables. However, she gains no pleasurable experience from eating fruit: given her gustatory tastes she finds the eating of fruit and vegetables highly unpleasant. Nonetheless, when she eats a banana instead of a chocolate bar she knows that this is in her best interests, and thereby contributes to her well-being, even though the experience is highly unpleasant. Likewise, an individual giving up smoking might find the process very uncomfortable and would gain more pleasure from continuing to smoke. However it is possible for this individual to recognise that her well-being will be improved if she discontinues smoking nonetheless. Consequently, since it is possible for certain actions to contribute to well-being without being accompanied by pleasurable experiences, the hedonist is unable to claim that well-being is identical with the experience of pleasure.

Thirdly, pleasurable experiences often accompany false beliefs. For example, I could feel pleasure from the belief that I am loved by my family. However, if this belief is false, then it is hard to see how the pleasure of falsely believing that I am loved by my family contributes to my well-being, since it is likely that were I to discover that I was being deceived by my relations I would not feel pleasure from the deception. Such examples support the central objection to the hedonist mental state theory that we often want our

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term experience of pleasure it provides) and to eat fruit (despite the short-term unpleasant experiences) because managing our diets in this way will lead to healthier lives, thereby leading to experiences of pleasure, and a reduction of suffering, in the long-term. Although I do not deal with this response here I will show in section 7.5 that a non-hedonistic objective list theory can more straightforwardly explain why choices regarding our health contribute to our well-being regardless of the long or short term pleasure it may or may not provide.

lives to go in ways that aren't pleasurable. In some areas of our lives we may prefer: "bitter truth to comfortable delusion" (Griffin, 2002: 9). The possibility that pleasure can be gained from false beliefs or faulty or incomplete information renders the hedonistic mental state theory an unsuitable account of individual wellbeing.

Notably, it is open to the hedonist to object that pleasurable experiences *in themselves* always contribute to individual well-being. This is because pleasurable experiences are always pleasurable, regardless of their origin or consequences. Instances in which pleasures appear to fail to contribute to well-being only do so because of circumstantial or consequential factors *aside* from the pleasurable experiences connected to them. For example, the badness of smoking is its ill effects on an individual's health. Nonetheless, some individuals find pleasure in smoking. To the extent that smoking produces pleasurable sensations it contributes to an individual's wellbeing. On this view, the badness of smoking should not be confused with it being bad *qua* pleasure (Frankena, 1973: 90).

Nonetheless, even if there can be no 'bad' pleasures it remains the case that pleasures are insufficient to account for individual wellbeing. Since the consequence of this position is therefore that if smoking is not bad *qua* pleasure then it is not detrimental to individual well-being. From a medical perspective, this is highly unintuitive. Indeed it turns out that factors aside from pleasurable feelings are needed to determine whether something will contribute to or detract from a person's wellbeing. If the goodness of pleasure can be outweighed by circumstantial or consequential factors as appears to be

the case with smoking, it remains the case that the maximisation of pleasurable experiences does not contribute to patient well-being.

### ***7.2.2 The Hedonic Mental State theory and Medical Decision making***

In terms of medical practice, maximising pleasurable experiences is straightforwardly incompatible with the duty of care and the preservation and protection of the patient's biological health (section 1.3). In medical decision making patients will often make decisions that they judge to be good for their health, and so in their best interests, but are accompanied by feelings of fear, anxiety or pain. In fact, it would be odd for all medical decisions to be accompanied by a feeling of pleasure, since many procedures will involve some sort of discomfort. Thus, in medical situations we may choose a painful procedure that protects our health because we recognise that it is in our best interests to suffer the pain in order to obtain good health. Moreover, this will be so even if it does not lead to long-term pleasure: for instance consider a case in which a patient has a mole removed in order to prevent skin cancer. Note that the mole itself is not causing her any pain and once the mole is removed she does not feel any additional pleasure. The procedure itself is mildly painful. Whilst it might be possible for someone to choose a medical option which fails to protect her health but makes her experience a high degree of pleasure, for example, the choice of drug induced elation instead of a medically necessary appendectomy, we can rightly judge that this is not in the sick patient's best interests. We thus: "...feel that there are things 'we should choose even if no pleasure came from them'" (Bradley, 1988: 88).

Likewise, patients and medical practitioners alike might reasonably view actions associated with pleasurable experiences as being detrimental to the patient's health. To be sure, individuals can find heavy drinking, smoking and over-eating highly pleasurable experiences whilst acknowledging that they are detrimental pursuits in terms of their health.

### ***7.3 DESIRE SATISFACTION THEORIES***

Desire satisfaction theories claim that an individual's well-being is improved just so long as her desires are satisfied. As applied to medical decision making, this account determines the outcome that is in the patient's best interests as the one which is likely to satisfy the patient's desire(s).<sup>49</sup>

Desire theories can be separated into 'actual' (section 7.3.1) and 'informed' (7.3.2) accounts. However, as I will show, neither of these sub-divisions suffices as an adequate account of individual well-being and so they cannot be used as a point of reference for determining patient best interests.

#### ***7.3.1 Actual Desire Theories***

Actual desire satisfaction accounts of well-being identify the desires that (when satisfied) contribute to well-being as those that the individual actually has. On my methodology, the actual desire theory of well-being would identify the medical option

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<sup>49</sup> Since desire satisfaction theories base individual well-being in terms of the satisfaction of individual desires it has strong links with absolutism (see Chapter 5). Indeed, proponents of absolutism have in fact argued that: "within a context of free and informed consent, the good for persons is the satisfaction of their autonomous desires" (White, 1994: 23-4).

that is in the patient's best interests as the one that satisfies the patient's actual desires. The actual desire account places a limited restriction on competent medical-decision making. A patient will be the best judge of what option will constitute her best interests if she correctly judges it as being likely to satisfy her actual desires. SJS would determine the nature of the incompetent patient's best interests in terms of what the patient would actually desire were she to be competent.

### ***7.3.2 Actual desires and epistemic disadvantages***

A central problem for the actual desire satisfaction account of well-being is that actual desires can be defective. There are five key ways (relevant to medical-decision making) in which an individual's actual desires can be faulty; an actual desire will be defective when:

- (1) the desire is based on incomplete information
- (2) the desire arises from flawed reasoning
- (3) the desire arises from faulty concepts
- (4) the content of the desire is determined by arbitrary factors
- (5) the individual might never know that her desire has been satisfied

Firstly, an individual's actual desire can be defective when (1) it is based on incomplete information. For instance, consider a patient who has the medical treatment options of a highly risky operation or taking a pill with limited side-effects. If the individual lacks correct information regarding the medical treatments available to her she may desire a

risky operation without realising that a pill will be just as effective. If the patient lacks information regarding the existence of the pill then her actual desire will cause her to choose an option that she would not choose were she to have complete information. It is not unreasonable to suppose that were the individual to be informed that the pill was equally efficacious she would withdraw her actual desire to have the risky operation. The satisfaction of actual desires based on incomplete information is insufficient for maximising well-being since it may lead a patient to choose an option that she would not have otherwise chosen. It therefore cannot always be in the patient's best interests to satisfy her actual desires.

Furthermore, there are things that we experience and judge to contribute to our well-being that we did not previously desire. For example, whilst attending a dinner party I might be offered an unusual food that I have never tasted before, thus having neither a particular desire nor an aversion towards it. i.e. like 4.2.1 I gave the example of lacking epistemic privilege with regard to what to order on the menu in an unfamiliar restaurant.

Nonetheless, I find eating this food an extraordinarily pleasurable experience which seems to contribute to my overall feeling of well-being. However, the enjoyment gained from eating the food cannot be conceptualised as the satisfaction of a desire since there was no desire to eat it before my experience of it. Nonetheless, I in fact judge it to contribute to my well-being without having actually desired it at all (Ross, 1927: 116-7). The satisfaction of an actual desire cannot be necessary for individual well-being in view of such examples.

Secondly, faulty desires may arise from (2) defects in an individual's reasoning. When an individual makes a logical mistake about the option that will best satisfy her actual desire then her actual desires will be poorly formed (Griffin, 2002: 12). To take an example from a medical setting, consider a patient who knows that she has been suffering from the common cold and has an actual desire to be treated on an accident and emergency ward. The patient incorrectly believes that she will be treated more efficiently on the emergency ward than if she arranged an appointment with her local GP. In fact, her reasoning is confused: the nature of an accident and emergency ward is to treat persons who are seriously ill or injured; she will thus not be attended to swiftly or effectively on the basis that she only has the common cold. In fact, she is more likely to get her desire to be treated satisfied if she attends her local GP's surgery. The patient's reasoning is confused, thereby rendering her actual desire faulty and the satisfaction of it inappropriate as a means of protecting her well-being. Once again, since the individual's actual desire is confused, its satisfaction does not guarantee the protection or promotion of her well-being. In the context of medical decision making the problem of faulty reasoning indicates that it cannot always be in a patient's best interests for her actual desires to be satisfied.

Thirdly, one's actual desires can also be mistaken if an individual has based her actual desires on defective concepts. For instance, an individual might be under the impression that health is solely something to be felt – she believes that if she feels healthy then she is healthy. Imagine that this individual is suffering from a broken arm. Due to her conceptualisation of health she decides that it is better for her health to take strong painkillers than to have her arm set in a cast. However, this individual's actual desire is

based on a defective conceptualisation of health. Although to a certain degree health is thought to be something that can be felt it is reasonable to suppose that it is also constituted by unfelt factors concerning the physical state of the body (see footnote 1, Chapter 1). Thus, whilst an individual may feel healthy, she may still be physically unhealthy. The satisfaction of actual desires that are based on faulty concepts are thus inadequate for protecting individual well-being, and thereby fails to account for the nature of patient best interests in medical decision making.

A further way in which an individual's actual desires can be faulty is that (4) an individual's actual desires can be determined by arbitrary factors. This fault with actual desires can be elucidated by returning to Wolf's example of JoJo as presented in section 5.3. Recall that JoJo is educated by his sadistic dictator father, Jo the First, and as a result develops values and desires very much like his father's, including: "...sending people to prison or to death or to torture chambers on the basis of the slightest of his whims" (Wolf, 1989: 143). Significantly, Wolf characterises JoJo as acting according to his own desires, thus when he tortures someone to death he does so on the basis of his actual desire. According to the actual desire account, if JoJo's actual desire is satisfied then JoJo's well-being is improved.

However, the case of JoJo and the theory of psychological determinism were used to highlight the inadequacy of the procedural account to determine when an individual's choice is authentic (her own) or inauthentic (influenced by outside factors). Given that I have already argued that an individual's actual desires may be psychologically determined it is doubtful whether or not the satisfaction of that actual desire will

contribute to her well-being. An extreme example in support of this claim is a case in which a patient has been hypnotised to desire the most painful medical procedure available to her. Her actual desire has been 'implanted' by the hypnotist in such a way that she endorses it on all levels of desire, but we would be wrong to suppose that the satisfaction of her actual desire for painful medical treatment would lead to an improvement in her well-being. Consequently, an actual desire account of individual best interests within the context of medical decision making is inadequate because it is not clear whether or not the patient's actual desire is in fact the patient's own.

Finally, the satisfaction of some of our actual desires cannot be necessary for our well-being since we may *never* know whether or not they have been satisfied. The difficulty lies in the fact that one's actual desires can be so broad that their satisfaction may be temporally and spatially distant from one's experiences. For example, I might desire that an acquaintance of mine with cancer goes into remission. After losing contact with her I never know whether she has survived the cancer or not. On the actual desire account my well-being is improved if her cancer goes in to remission, even if I am unaware of this fact or if her cancer goes into remission after my death.

But it is hard to see how facts about the world that are inaccessible to the individual can affect her well-being. Unless I am aware that my desire has been satisfied, its satisfaction will not touch me in a way that could affect my life, let alone improve it. Indeed, in cases where I do not know whether my desire has been satisfied or not, the desire might as well remain unsatisfied. Since the satisfaction of many of my actual desires: "...will occur at times or places too distant from me to have any discernible effect on me. In such cases

it is difficult to see how having my desire satisfied could possibly benefit me.” (Sumner, 2000: 7). The actual desire account is too ‘broad’ to meaningfully affect our well-being, and so the satisfaction of actual desires is an inadequate account of individual well-being. For this reason, it is not in an individual’s best interests to satisfy her actual desires if she will never be aware that they have been satisfied.

There are good reasons to suppose that the actual desire account does not provide a complete account of individual well-being. The account is inadequate because it is possible to have actual desires for states of affairs that are detrimental to personal well-being. This will be the case when actual desires are based on incorrect information, an individual’s defective reasoning or concepts and when they are determined by arbitrary factors. Actual desires that are subject to these flaws could in fact lead to a decline in well-being when satisfied; the satisfaction of actual desires therefore cannot be a sufficient component of individual well-being. Furthermore, the actual desire account cannot be a necessary condition of patient well-being because it is reasonable to suppose that an individual’s well-being can be improved by experiences that she has never actually desired, and unreasonable to suppose that an individual’s well-being can be improved when her actual desires are satisfied without her knowledge (7.3.1.2). For all of these reasons, the actual desire account of well-being is unable to determine the content of a patient’s best interests in a given conflict in medical decision making.

For this reason I claim that it cannot provide an answer as to what constitutes a patient’s best interests in medical decision making: whether a particular medical option will lead

to the satisfaction of a patient's actual desire does not provide grounds for supposing that the medical option is in the patient's best interests.

### **7.3.3 Informed Desire Theories**

I have shown that the actual desire satisfaction account fails to provide an adequate account of individual well-being, and therefore is unsuitable as a theory to be used for determining patient best interests. In this section I look at the informed desire satisfaction account of individual well-being and also reject it is a suitable model for determining patient best interests.

Informed desire accounts of well-being attempt to bypass the problems faced by the actual desire account, by requiring that the actual desires that contribute to well-being are those that one would have if they were based on *correct information*. The informed desire account is thus a narrower version of the actual desire account; the desires that contribute to well-being are not those that individual actually has, but are rather those desires that an individual would have were she to appropriately informed.

However, the attempt to address the failings of the actual desire account by restricting the type of desire that contributes to well-being to those that the individual would have were she to be adequately informed suffers problems of its own. As I will show, each of these problems stem from the difficulty of determining the amount of information required for a desire to count as being informed.

### **7.3.4 Informed Desires and the Reality Requirement**

A theoretical difficulty with the informed desire account is determining how much information is needed for a desire to be relevantly informed. The strongest information requirement demands that the informed desires that contribute to well-being (when satisfied) are based on information that reflects reality. This *reality requirement* demands that in order for the satisfaction of a desire to contribute to individual well-being it must be perfectly informed (Sumner, 2000: 17). The reality requirement classes informed desires as ones: "...that are based on a full understanding of the nature of their objects" (Scanlon, 1999:114). A desire is informed enough for its satisfaction to contribute to individual well-being when it is based on information which fully reflects the nature of reality. Note that the individual does not have to *actually* have the desire. Indeed, it does not mean that the individual needs to have full knowledge of the nature of reality. It is rather a counterfactual account of best interests. It is in an individual's best interests for something to happen to her if it is something that she would desire were she to be fully informed.

Consequently, on my methodology, it would be in a patient's best interests to select the medical option that would most likely satisfy the desire(s) she would have were her desire to be perfectly informed in line with reality.

There is good reason to suppose that the reality requirement leads to an overly demanding constraint on informed desires, and thereby an overly demanding account of well-being since there will be cases where no information is available about the full nature of medical treatment, either because there is no expert information on hand, or

because no factual information is available. Indeed, within medical practice there are situations in which there is no information available as to what the patient would desire were full information available. The difficulties of determining the nature of informed desires is reflected in the epistemological difficulties of obtaining informed consent in research. Such difficulties are particularly present when attempting to obtain informed consent for some forms of medical research, for example with biobanking. Biobanks provide a database of human tissue and medical information which can be accessed by future researchers. The nature of the medical research utilising this collection is largely unknown at the time of seeking consent. Although some of the particular research projects might be known when the research subject's data is collected: "the resource will also be used for research that is not yet imagined – so the kind of detailed information about the purpose, methods, risks and benefits usually considered essential cannot be given" (Allen and McNamara, 2009: 3). Problematically, there is often no information available to the biobank researcher as to the nature of future research at the time informed consent is sought from the potential donor (Bullock and Widdows, 2011: 111).<sup>50</sup> On the informed desire account of well-being (under the reality requirement) whether or not it is in an individual's best interests to donate her tissue to a biobank is fundamentally unknowable. It would therefore be impossible to determine whether a patient's consent, and thereby the satisfaction of her desire for her tissue to be used for research, is in her best interests.

Of course, it is open for the defender of the informed desire account to insist that the satisfaction of informed desires provides a complete account of well-being, it perhaps

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<sup>50</sup> The following discussion on the paucity of information when attempting to obtain informed consent in medical research is adapted from my paper (Bullock and Widdows, 2011: 111-6).

just turns out that individuals do not know when their desires are informed enough: if an individual satisfies a desire that just so happens to be one that she would have were her desire to be fully informed then it turns out that her well-being is improved.

However the unknowable content of informed desires causes problems for medical decision making. Indeed, under the reality requirement, if the nature of an individual's well-being is unknown because her informed desires are unknown the medical option that is in the patient's best interests would also be unknowable making the informed desire account an unworkable theory of identifying patient best interests in medical practice. This is a problem for both hard paternalism and soft paternalism: the hard paternalist will be unable to assess whether or not the competent patient's desire is fully informed nor able to predict what she would desire were her desires to be perfectly informed. Nor will the soft paternalist, using SJS, be able to determine what the incompetent patient would have desired were she to have been competent and fully informed. If there is no information available then it appears that there is no way of determining which medical option it would be in the patient's best interests to choose.

### ***7.3.5 Informed Desires and the Justification requirement***

Due to the overly demanding features of the reality requirement proponents of informed desire accounts of well-being have adopted a weaker constraint on the sort of information needed for a desire to be relevantly informed. The justification requirement classes the informed desires that (when satisfied) contribute to individual well-being as the ones that are based on 'adequate' information. Instead of requiring that the informed

desires required for well-being coincide with the nature of reality, the justification requirement holds that the informed desires that contribute to well-being are ones that are 'adequately' informed within a given context.

Although less demanding than the reality requirement the justification requirement is subject to further problems. The main difficulty with the justification requirement stems from the need to determine how much information is required for a desire to count as being 'justifiably' informed. In the following I present and reject two theories which attempt to determine the adequate level of information required for a desire to be justifiably informed, namely:

- (a) The context-sensitive account, and
- (b) The subjective assessment account

As I will show, (a) the context-sensitive account fails to provide an account of justifiably informed desires because the account relies upon an indefensible asymmetry between desires that can be easily informed and those that are harder to inform (section 7.3.5.1). Furthermore, I will show that (b) the subjective assessment account fails to provide an adequate account of the justification requirement since it is possible for an individual to mistakenly assess that her or his desires are justifiably informed (section 7.5.3.2).

### ***7.3.5.1 Context-sensitivity***

One approach to determining whether a desire is adequately informed would be to make the justification requirement sensitive to the context in which the desire is formed and continues to be maintained. In contexts where the relevant information is difficult to obtain the individual's desire will be justifiably informed on the basis of minimal information. Conversely, in situations where the availability of information is ample an individual's desire will be justifiably informed if it is based on full information. No doubt the level of information required for a desire to be classed as justifiably informed could be measured on a sliding scale; the more accessible the information, the more informed a desire has to be in order for its satisfaction to contribute to individual well-being. The less accessible the information, the less information is required for a desire to be informed and to contribute to individual well-being upon its satisfaction.

However, the context-sensitive interpretation of the justification requirement is unable to account for the connection between the satisfaction of informed desires and individual well-being because it requires an asymmetry of demands between desires that can be easily informed and a leniency towards desires that are difficult to inform. Aside from reasons of convenience, it is simply not clear why desires can be less informed in difficult circumstances or why desires must be fully informed in simplistic circumstances and contribute equally to well-being.

Moreover, it is probable that those situations in which information is difficult to obtain are the ones in which information is *most* needed to inform a desire and thereby protect well-being. Intuitively, the more difficult the informational context, the more

information would be needed to protect the well-being of the individual.<sup>51</sup> We thus have reason for rejecting a context-sensitive account of desires that are justifiably informed.

### ***7.3.5.2 Subjective assessment***

An alternative account of the justification requirement measures the degree of information required for a desire to be informed in terms of the individual's 'subjective assessment'. On this standard, the degree of information needed for a desire to be informed and thereby contribute to well-being ultimately lies with the discretion of the individual. It is contended that: "[t]he relevance of information for a person's well-being is a personal matter to be decided by personal priorities; there is here no authoritative public standard" (Sumner, 2000: 18). Thus, in cases where it is difficult to process information, a desire will be informed enough for well-being if the individual considers it to be so.

However, as I will show, it is possible for the individual to incorrectly judge that her desire is adequately informed. In such circumstances it will be possible that a desire which the individual falsely judges to be adequately informed will not improve her well-being when satisfied.

Cases in which an individual fails to judge that her desire is not adequately informed will arise when the individual does not realise that her desire is based on faulty information.

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<sup>51</sup> Indeed, as I will show in section 9.2.3.1 in cases of complex decision making patients perform poorly in terms of understanding and retaining information regarding the risks of certain procedures. It would thus seem that - if the informed desire account is to be endorsed - that when making complicated decisions a patient's desires must be very well informed.

Indeed, an individual could form a faulty judgement as to whether her desire is informed enough if it is based on what she fails to realise is incorrect information. Consider a case in which an individual seeks medical advice from a website regarding her symptoms of nausea and vomiting. She concludes that she has some form of mild food poisoning from her meal the night before. Satisfied with the information she has procured she fails to form a desire to see her GP. She fails to realise that she has an undiagnosed peptic ulcer which will lead to a further deterioration in her health. Reliance upon an individual's subjective assessment of the adequacy of information will, in some instances, fail to protect well-being in the medical context because she might judge minimal information as adequate, when in fact it is not.

In response to this form of objection, Sumner argues that we have a reason to intervene with the individual's subjective assessment as to whether her desire is informed if we believe her assessment to be inaccurate (Sumner, 2000: 18). Thus, in the case of the inadequately informed individual in the previous example who found it unnecessary to go to her GP because she was satisfied with the information she found on the internet regarding her symptoms, we have a reason to suspect that the satisfaction of her desire to stay at home and recover in bed will not contribute to her well-being. We have a good reason to suppose that her subjective assessment as to whether her desire is adequately informed is faulty and so have reason to interfere with it.

This, however, is an unsatisfactory response because it shows that subjective assessment of information is neither necessary nor sufficient for determining the amount of information required for an informed desire to contribute to individual well-

being. Indeed, if there are cases in which we can judge that an individual's subjective assessment of her informed desire is wrong, then the subjective assessment account does not provide an account of the sort of information that is adequate for a desire to be informed and thereby contribute to individual well-being. Whilst it is possible for the intervener to use an informed desire account of well-being to justify her intervention, i.e. by drawing upon information that the individual has dismissed – such as other symptoms indicating the presence of a peptic ulcer, or in terms of the reality requirement, the existence of a peptic ulcer, the intervener will need to provide an account of why the individual's desire is not based on adequate information. We are therefore still lacking an account of the amount of information required for a desire to be justifiably informed. Without a circular appeal that the justified amount of information is that which contributes to well-being, it is difficult to see how the proponent of the informed desire account can provide an account.

### ***7.3.6 The inadequacy of informed desire accounts***

Informed desire accounts were supposed to avoid the unrestricted nature of actual desires, the satisfaction of which was claimed to constitute individual well-being. Nonetheless, the informed desire account has been shown to have its own failings.

The central problem with the informed desire account stems from the need to determine how much information a desire must be based upon in order for its satisfaction to contribute to well-being. Although both stronger (the reality requirement) and weaker (the justification requirement) accounts have been developed, neither succeeds in

providing a standard of information that can be plausibly required in an account of well-being. The strongest information requirement demands that an informed desire is based on information that reflects reality. This *reality requirement* demands that an individual is *perfectly* informed about the objects of her desire in order for the satisfaction of that desire to contribute to individual well-being (Sumner, 2000: 17). However this requirement was shown to be overly demanding in terms of medical situations where such information is unavailable.

A weaker requirement stipulates that a desire must be based on a justifiable amount of information in a given context in order for its satisfaction to contribute to individual well-being, either in terms of the context (section 7.3.5.1) or in terms of the individual's subjective assessment (section 7.3.5.2). However these weaker informational requirements were also shown to provide a poor analysis of well-being given that an extremely high amount of information will still be required to ensure that a desire is informed in medical contexts where information is unavailable and moreover that it is possible for an individual to mistakenly assess her desire as being adequately informed. For these reasons the context-sensitive and subjective assessment account of the justification requirement are unable to provide an adequate account of the content of informed desires, and thereby do not provide an account of well-being that can be used for determining patient best interests.

#### **7.4 DESIRE SATISFACTION ACCOUNTS AND THE HARM\* PRINCIPLE:**

In the preceding sections of this Chapter I have noted some possible problems with desire satisfaction accounts of well-being. In this section, however, I argue that even if more complicated desire satisfaction accounts of well-being could be (or have been) developed there remains an insurmountable difficulty of adopting a desire satisfaction account of well-being in medical practice. Specifically that it is always possible for an individual to have a non-prudential desire (Arneson, 1999: 125).

The main difficulty of the desire satisfaction account is that it is possible to actually desire states of affairs that are detrimental to individual well-being whether or not the desire is adequately informed. For instance, an individual might desire to self-mutilate, or binge on food, or just generally desire to cause harm to herself. Indeed, there are numerous things that we judge to be antithetical to well-being that an individual may desire (Ross, 2007: 101). It is therefore not the case that the satisfaction of my desires, informed or not, will contribute to my well-being. Consequently, it cannot be in an individual's best interests to make decisions on the basis that it will satisfy her desires.

The proponent of a desire account could claim that we are mistaken in the supposition that individuals can desire things which are detrimental to well-being. Well-being just *is* the satisfaction of desires, regardless of the content of the desire or the means by which it is satisfied. However, in order for such a response to be plausible, such an objection relies upon the absolutist conception of harm\* expounded in section 3.1. It was shown there that the absolutist definition of harm\* states that an individual cannot be harmed\* by that to which he has consented. It is reasonable to construe the actual desire account

as relying upon the harm\* principle since the proponent of the actual desire account would have to hold that the perceived harm of the individual's exercised choice is outweighed by the harm\* that would be caused by preventing her from satisfying this desire. Pellegrino and Thomasma go so far as to suggest that such an account allows for the possibility that an individual can desire things which are bad or injurious, but that the satisfaction of these desires still contributes to their well-being. Just because we do not agree with them does not mean that the individual's interests aren't harmed\* if we deny them the satisfaction of their 'bad' desires (Pellegrino and Thomasma, 1988: 80).

However, this conception of harm\* should be rejected in view of other ethically significant factors which we intuitively regard as contributing to well-being. Indeed, in terms of public law, Davis accurately observes that a patient's express consent: "...may be insufficient to override the public purposes that justify the illegality of the activity in the first place" (Davis, 2003: 368-9).<sup>52</sup> This is because consent is inadequate for waiving certain human rights. Determining the legitimacy of rights-waiving has been shown to be problematical. In *R v. Brown* (1993) sadomasochists - found to have committed acts of violence upon one another: "...including genital torture, for the sexual pleasure which it engendered in the giving and receiving of pain" (*R v. Brown*, 1993: 76) - were convicted of assaults occasioning actual bodily harm. An appeal was made against the conviction under the contention that: "...a person could not guilty be [sic] of assault occasioning actual bodily harm or unlawful wounding in respect of acts carried out in private with the consent of the victim" (*R v. Brown*, 1993: 76). As part of their appeal

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<sup>52</sup> The following discussion of rights-waiving and the scope of consent is taken from my paper (Bullock, 2010).

they thus proposed that individual consent was sufficient to waive rights to bodily integrity.

However, individual consent was found to be an insufficient justification for the waiving of this right. As Lord Jauncey of Tullichettle noted: "...there must be some limitation upon the harm which an individual could consent to receive at the hand of another" (1993, 86). The consent of the sadomasochists was found by the court to be insufficient to waive their rights to bodily integrity. As this example shows, before the waiving of human rights can be accepted as being ethically justifiable it is necessary to discern the conditions under which it is morally legitimate.

Furthermore, the ethical insufficiency of rights-waiving is presented by Beyleveld and Brownsword in an example of the inadequacy of a patient's consent to an illegal medical procedure: "...whilst a patient's consent might be sufficient to constitute a defence to shield a doctor against a claim by the patient, it does not necessarily render the act lawful. If the act in question was, say, an abortion: "...the doctor might still have to answer to the authorities for his actions" (Beyleveld and Brownsword, 2007: 16). In this scenario, the patient's consent to an abortion, thereby waiving her rights to bodily integrity (and perhaps even the child's right to life) does not make the act ethically justified. Consent alone is thus unable to fully explain the ethical legitimacy of medical procedures. This shows that the absence of harm\* is insufficient for guaranteeing that an action is ethically justified.

In order to defend the claim that the satisfaction of a desire (informed or actual) defines individual well-being the theory must rely on the harm\* principle, specifically that so long as an individual isn't harmed\* then her exercisable free choice, thereby satisfying her desire, should be respected. However, the supposition that exercisable free choice should be respected in instances where patients can be harmed has already been rejected in Chapter 6 with my rejection of absolutism.

### **7.5 OBJECTIVE LIST THEORIES**

An objective list account of well-being, also referred to as a 'substantive good' theory of well-being (Scanlon, 1993: 189), differs from the hedonic mental state (7.2), actual desire satisfaction (7.3.1) and informed desire satisfaction (7.3.3) accounts insofar as it defines individual well-being independently of the individual's tastes and desires (Scanlon, 1975: 658). Whereas previous accounts were based on the individual's subjective assessment of how well her life is going (i.e. feeling of more pleasure than pain), or dependent on the subject's desires, an objective list account captures individual well-being by determining substantive goods in a way that is not solely<sup>53</sup> dependent upon a person's experiences or the satisfaction of her actual or informed desires:

The idea of the objective list is simply that what is intrinsically good for a person is fixed independently of that person's attitudes or opinions; the items on the list for an individual are there independently of whether the individual has favourable attitudes toward them or himself judges that the items are valuable for him (Arneson, 1999: 118-9).

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<sup>53</sup> Indeed, an item on the list might include desire-satisfaction or hedonic experiences. The objective list differs in that well-being is not *reducible* to either of these substantive goods.

Since the objective list account of well-being is independent of the individual's preferences and desires then it is possible for the account to determine that something will contribute to an individual's well-being even if it directly *conflicts* with that individual's preferences or, actual or informed desires:

What is essential is that these are theories according to which an assessment of a person's well-being involves a substantive judgement about what things make life better, a judgement which may conflict with that of the person whose well-being is in question (Scanlon, 1993: 188).<sup>54</sup>

The conflict between individual preferences and objective well-being is evident in the context of medical practice. Indeed, such a conflict reflects the tension between the duty of care and the doctrine of informed consent presented in section 1.4. Consider a situation in which a medical practitioner believes that it is in a breast cancer patient's best interest to have a double mastectomy. The patient herself - suppose that she is a glamour model - objects to the medical procedure; she desires to continue her modelling work even if this means her life is shortened. An objective list theory of well-being could explain why this conflict has arisen: the medical practitioner (under the duty of care) believes it is in the patient's objective best interests to recover her health whilst the patient's preference (under the doctrine of informed consent) is against having the surgery.<sup>55</sup> Moreover, the patient's aversion to the procedure thought to be in her

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<sup>54</sup> The claim that items on the objective list can conflict with an individual's desires has led some theorists to adopt what Arneson refers to as an 'endorsement constraint.' This constraint amounts to the view that: "...nothing counts as an objectively valuable attainment unless it is subjectively affirmed by the one who has gained the attainment" (Arneson, 1999: 135). However, although not fully addressed here, I find Arneson's rejection of the endorsement requirement as convincing since it is plausible to assess a person's failure to endorse an objective good, not as diminishing the contribution of that good to her well-being but rather that her evaluation is mistaken. Therefore: "...this nonendorsement does not automatically or necessarily alter [the value of an objective good]" (Arneson, 1999: 137).

<sup>55</sup> This conflict can arise regardless as to whether the preference is actual or informed (Scanlon, 1975: 658).

objective best interests need not be a short term conflict. Indeed, the objective list allows that something can be in an individual's best interests even if they *never* come to agree that it contributed to their well-being. Thus if we have good reason for supposing that the medical practitioner's determination of the patient's best interests is objectively correct then performing the mastectomy is in the patient's best interests despite the patient's long or short-term aversion to it.<sup>56</sup>

Notably, it is possible for there to be only one item on the objective list, in other words, one substantive good. For this reason, the hedonic mental state account (7.2) can be understood as an objective list account of well-being so long as the only substantive good that is allocated on the list is that of experiencing pleasure (Scanlon, 1993: 189).<sup>57</sup> It is also worth considering the possibility that the exclusive substantive good contributing to well-being on the objective list is the exercise of free choice. If this were to be the case then the adoption of absolutism (chapter 5) would be the best method of protecting individual well-being, since the only constituent of well-being would be the exercise of free choice: the more often an individual exercises her free choice the better her life will be. In terms of medical practice, an objective list theory with the sole entry of exercising free choice would support the unqualified use of informed consent procedures, regardless of its conflict with the duty of care. However, such a position has already been fully rejected in chapter 6 and so I will not return to those arguments here.

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<sup>56</sup> The absence of long term endorsement of an interference with a patient's choice is explored in Chapter 9 as part of my justification of hard paternalism.

<sup>57</sup> The failure of hedonism to provide an adequate account of well-being has been fully explored in section 7.2

A benefit of the objective list account is that it can include things that we intuitively regard as being valuable, such as pleasure, desire-satisfaction and free choice without reducing an account of well-being to either one of these goods. It can thereby bypass the problems faced with these accounts by incorporating other goods that we intuitively regard as contributing to well-being *in addition to* instances where pleasure or desire satisfaction or free choice do in fact seem to contribute to well-being. Indeed, objective list accounts, such as the following one derived from Sidgwick, Moore and Ross generally contain more than one item including substantive goods such as:

1. Life, consciousness, and activity
2. Health and strength
3. Pleasures and satisfactions of all or certain kinds
4. Happiness, beatitude, contentment, etc.
5. Truth
6. Knowledge and true opinion of various kinds, understanding, wisdom
7. Beauty, harmony, proportion in objects contemplated
8. Aesthetic experience
9. Morally good dispositions or virtues
10. Mutual affection, love, friendship, cooperation
11. Just distribution of goods and evils
12. Harmony and proportion in one's own life
13. Power and experiences of achievement
14. Self-expression
15. Freedom

16. Peace, security
17. Adventure and novelty
18. Good reputation, honour, esteem etc. (Frankena, 1973: 87-8).<sup>58</sup>

Both (4) happiness, and (15) freedom are included on this list, but other substantive goods are also included. According to this account it is therefore possible that in some instances the medical decision that will be in the patient's best interests, thereby contributing to her overall well-being, might not involve making the patient happy or respect for her free choices. The adoption of an objective list account thus helps resolve some of the conflicts experienced between informed consent procedures and the duty of care (section 1.4). If for example the patient's (15) Freedom of choice comes into conflict with her (2) Health or her (1) Life, the objective list does not guarantee that her freedom of choice has priority. Satisfaction of (2) Health and (1) Life might contribute to her well-being more than respecting her freedom to choose her medical treatment. The objective list theory of well-being provides a basis for balancing different substantive goods in different situations beyond relying upon a demand to respect patient free choices as required by the doctrine of informed consent.

A central suspicion with objective list theories of well-being is how the items on the list are determined or chosen. Critics have charged against the objective list theory that the items on the list can only be (1) arbitrarily chosen, and when chosen are (2) too rigid to account for the differences in individual values and interests: "...as if the same things must be valuable for everyone" (Scanlon, 1993: 188). It is thus objected in the second

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<sup>58</sup> The items on this list are not presented in any order of priority.

case that an account of well-being cannot be the same for all human beings but must be relative to the individual whose well-being is in question (Arneson, 1999: 117).

In the following section (7.5.1) I address the concern that the items on an objective list can only be arbitrarily chosen and defend the case that the attribution of substantive goods on a list can be decided intuitively. In section 7.5.2 I respond to the objection that objective list theories of well-being are overly rigid by explaining how a substantive account can provide a subject-relative account of individual best interests.

### ***7.5.1 Objective Lists, Arbitrariness and Intuition***

The first concern with an objective list account of well-being is that the substantive goods that feature on it can only be chosen arbitrarily. In this section I look at three possible responses to this concern, specifically the theses that the items on the list can be determined in light of:

- (1) A theory of basic needs
- (2) intersubjective agreement, and
- (3) intuitionism

I will reject the basic needs account (1) on the basis that the resulting list provides an implausibly narrow account of individual well-being. Secondly, I reject the intersubjective agreement account of substantive goods (2) because it could end up endorsing accounts of well-being that have already been rejected, or include items on

the list that we regard as being intuitively bad. Ultimately I defend the position that the items on the list must be determined through (3) intuition. Moreover, I argue that this intuitionism need not be thought of as a flaw of the objective list theory, since my objections to the hedonic mental state theory and desire satisfaction accounts were similarly based on intuition. Thus although such a list is intuitive, this does not mean that it is arbitrary.

Firstly, a basic needs approach to determining the items on the objective list supposes that the sorts of things that contribute to well-being are those that are required for human functioning, the: "...needs we all have just by being human" (Griffin, 1986: 41). This 'naturalistic' approach to determining the items on the objective list supposes that the sorts of things that objectively contribute to individual well-being are those that preserve human life (Wisniewski, 2011: 1). Basic needs will thus include such things as: "...food to survive, rest to go on functioning, health to do much of anything" (Griffin, 1986: 42).

It might be thought that the basic needs account of substantive goods is similar to desire satisfaction accounts on the basis that the items on the list of needs are also desirable. However, the basic needs account of the substantive goods that are to appear on an objective list differs because the meeting of a basic need will contribute to the individual's well-being regardless as to whether the individual desires their satisfaction. To take an example, consider the case of a patient suffering from anorexia nervosa<sup>59</sup> that

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<sup>59</sup> The controversy surrounding whether or not a patient suffering from anorexia nervosa can be competent to refuse medical treatment or forced nutrition has already been explored in section 2.1 where

has an aversion to food. Although she does not desire to eat food, in terms of her biological functioning as a human being she needs food to survive. The basic needs account will determine that it is in the anorexic patient's best interests, in the sense that it will contribute to her objective well-being, if her need for food is satisfied. The difference between basic needs and desires is therefore that the former are independent of the person's individual desires and preferences.

There are two ways of defending the basic needs account of the objective list theory. Firstly, their satisfaction can be interpreted as an instrumental means for achieving any desires or values the individual may have. On this account, the motivation for this attribution of items on the objective list is that being healthy is a prerequisite for satisfying any desire peculiar to the individual: "[s]ince a sufficiently healthy life is a prerequisite of forming and acting on any desires whatsoever, life and health preservation seems to be a good candidate for an objective requirement of well-being (Wisniewski, 2011: 1). Secondly the basic needs account may be defended as defining the substantive goods that intrinsically contribute to individual well-being. I argue that neither of these accounts succeeds in providing a suitable account of objective well-being. In the first case where basic needs are regarded to be instrumental to satisfying desires the problem arises that an individual's desires can conflict with her basic needs. Secondly, I reject the basic needs method because it provides an overly narrow account of individual well-being.

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it was shown that anorexic patients can pass the Mac-CAT test for competence, although they may be prevented from exercising their free choice in practice under the mental health act 2007.

In the first instance, it is insupportable to defend a basic needs account of the objective list theory on the basis that it will be instrumental to enabling an individual to pursue her desires and preferences since, as has been repeatedly shown, often an individual's desires will conflict with her best interests (sections 1.3, 6.2 and 7.1-7.4). Problematically, it is therefore possible that the individual's desires and preferences are opposed to items on the basic needs list, such as health, nutrition, or rest. Perhaps it is possible for the basic needs account of the objective list theory to impose a restriction on the sorts of desires and preferences that will contribute to well-being; as such the only desires and preferences that contribute to well-being would be those that are compatible with the individual's objective basic needs. However, if this is the case then the patient's desires seem to be irrelevant to the determination of her well-being, since the only desires that will contribute to her well-being are those that are compatible with her basic needs.

An alternative defence of determining the items on the objective list in terms of basic needs is that such needs, when satisfied, *intrinsically* contribute to individual well-being. On this account, the satisfaction of basic needs contributes to objective well-being, without being a means to anything else, because they are natural features of functioning human beings. Such a conception of objective well-being is compatible with some interpretations of the goals of medicine. Cassel has argued that a central goal of medicine is to restore and maintain the physical and psychological health of the patient (Cassel, 1977: 18). On this conception it has thus been posited that health is *intrinsically* valuable because the human body is predisposed to heal itself:

[t]he body left to itself tends to heal...Health is the end toward which the living body as a biological organism tends, and it is in this sense that it becomes an absolute intrinsic value of the living body (Pellegrino and Thomasma, 1988: 64).

Certainly, a central goal of medicine is to restore and maintain the physical and psychological health of the patient (Cassell, 1977: 18). The preservation of health is recognised to be a goal of medicine because it facilitates the natural tendency of the body to heal itself.

However, there are two difficulties with this account. Firstly, it has been objected that a difficulty with the account is that the basic needs account's reliance on natural features of human functioning is unable to distinguish between healthy and diseased features of human life. Indeed: "...if 'natural' is to be understood as 'occurring in nature', then, clearly, we would have to count as healthy many naturally occurring characteristics that medicine classifies as diseased (diabetes, Down's syndrome etc.)" (Wisniewski, 2011: 2). A naturalistic approach is problematic because there are many natural features of human life which we are disinclined to think of as contributing to individual well-being.

The second difficulty with using a basic needs account of objective well-being is that it reduces the focus of well-being to healthy functioning. Such a conception of well-being has been criticised in the context of medical decision making since if biological functioning were to be the sole goal of therapeutic medicine then medicine would be limited to technically right interventions (Pellegrino and Thomasma, 1988: 78) and the aim of medicine would be to keep the patient alive for as long as possible (Cassell, 1977: 19). If this were to be the case then certain medico-ethical issues such as quality of life

judgements, or whether or not the patient's life is *worth* living – could not be assessed within the realm of medicine since the only purpose of medicine would be to aid biological functioning for as long as possible (Pellegrino and Thomasma, 1988: 79).

However, the view that the *sole* aim of medicine is to protect, restore and promote the biological health of the patient is insupportable because it fails to acknowledge competing goods that we tend to think of as also contributing to the patient's well-being. The sole identification of the goal of medicine with the protection and restoration of biological functioning fails to address other features of well-being such as: "...pleasure, travel, wealth, prestige, independence from physicians, or family togetherness" (Pellegrino and Thomasma, 1988: 61).<sup>60</sup> Reducing well-being to any one thing that we regard to be substantively good is problematic because it seems to leave out other things that we consider as contributing to well-being. Given the multiplicity of goods that may constitute a patient's best interests at a given time the good of health should therefore be treated as a relative value, its value being constrained in terms of its relation to other goods. The naturalistic approach does not succeed in providing a plausible account of the items on the objective list.

As noted, a second approach for determining the items on the objective list is by selecting the ones that are (2) intersubjectively approved: "...one possible form that an objective list theory could take would be to ground its objectivity in the intersubjective agreement of agents" (Varelius, 2003: 367). Notably, the allocation of items on the list

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<sup>60</sup> Pellegrino and Thomasma argue that these alternative features of well-being appear because they are ones that the patient might subjectively hold in higher esteem than her health. However, beyond Pellegrino and Thomasma's understanding it is equally possible that the basic needs approach fails to take into consideration the existence of other features of well-being on the objective list.

through intersubjective agreement means that the list is no longer objective since the items on the list are dependent on widespread agreement. Varelius does not find this implication problematic because such a theory: "...would at least not be subjective in the sense that the agent's subjective attitudes would not be sufficient to make something prudentially good for the agent" (Varelius, 2003: 367). Equally, Wisniewski has defended the intersubjective approach on the grounds that, when reduced to social facts, the items on the list are easily known (Wisniewski, 2011: 1-2). Nonetheless, as I will illustrate, we should be wary of relying upon the intersubjective method for determining the items on the objective list.

Firstly, reliance on intersubjective preferences for determining the items on the objective list could result in the endorsement of a hedonistic mental state account, or desire satisfaction accounts of well-being. Consider, for example, a possible world in which it is intersubjectively agreed that the sole contributing factor to well-being is the experience of more pleasure than pain – in other words, that it is intersubjectively agreed that the hedonic mental state account of well-being is true. If this were to be the case then it would be in the best interests of an individual to plug into Nozick's experience machine (see section 7.2.1). However, as we have seen, there are good reasons for rejecting the hedonic mental state account of well-being, especially in the medical arena (section 7.2.2). It would be odd that these concerns could be eliminated purely because individuals were of the opinion that the hedonic mental state theory provides a complete account of individual well-being.

A second worry stems from the possibility of intersubjective agreement that well-being is constituted by things that we regard as being substantively bad. In this situation it might be intersubjectively agreed that an item on the objective list is torturing animals so that an individual's well-being is improved the more often she kicks a dog. Thus, not only might it be intersubjectively agreed that the hedonic mental state account or desire satisfaction theories provide accurate accounts of individual well-being, it could also turn out that items we intuitively consider as being substantively bad could end up on the list. For this reason, we should not rely upon intersubjective agreement when determining the items on the objective list. Indeed:

...it is not clear why we should give this standard any moral weight. If we did, we should merely detach well-being from objective features of human nature and connect it instead to accidental social changes that have no obvious moral significance (Griffin, 1986: 44).

When we recall that the objective list theory is also known as a substantive good theory it is clear why intersubjective agreement fails: those things that are substantively good are independent of personal preferences, even if those preferences are widely shared.

With the problems surrounding the (1) basic needs account, and (2) intersubjective agreement my claim is that we can rely upon (3) intuitionism when drawing up a list of substantive goods to feature on the objective list. Such a process might include a reference to basic needs and intersubjective agreement, without reducing the items on the list to either account. Likewise, an intuited objective list could also refer to hedonic mental state and desire satisfaction accounts when it seems plausible that such elements

contribute to well-being, but without claiming that pleasurable experiences or the satisfaction of desires are the only things that contribute to individual well-being.

Thus when the appeal to basic needs seems implausible because it includes diseased features of human functioning on the list, or the appeal to intersubjective agreement leads us to include things we suppose are substantively bad on the list, then we can rely on intuition to resolve the conflict. The advantage of intuitionism is thus that it can draw upon a multiplicity of theories of well-being.

There is no need to regard the substantive goods that appear on the objective list as being arbitrary simply because they are intuitive, since the development and rejection of theories of hedonic mental state theory (7.2) and desire satisfaction theories (7.3) were also based on our intuitive responses to certain situations (Crisp, 2008). For instance, with regard to the hedonic mental state theory it was argued that one should not plug into the experience machine because there are other things we intuitively regard to be of value, such as being in touch with reality and directing one's own course in life, *regardless* as to whether someone strongly desires to plug into the machine (section 7.2.1). Similarly, a general rejection of desire satisfaction accounts was that it is possible to desire states of affairs that are detrimental to individual well-being (section 7.4). This rejection is only plausible if we accept the intuition that the desire for self-mutilation or the desire to binge on food is detrimental to individual well-being when satisfied. The claim that the items on the objective list should also be determined intuitively need not provide cause for thinking that the theory is arbitrary, and thereby nor is it reason for rejecting the account.

### 7.5.2 Objective Lists and Rigidity

The second objection to objective list theories of well-being is that they are too rigid to account for variations in individual well-being. It is contended that whatever is included on the list there are likely to be persons who do not want certain things to appear on it, and for other items that are not included, to want them included. In order to illustrate this concern Griffin uses the example of: “[a] group of scholars [who] may, with full understanding, prefer an extension to their library to exercise equipment for their health” (Griffin, 1986: 45). In this instance, the scholars regard their well-being to be constituted in the furtherance of their knowledge, rather than in an improvement in their health. According to Griffin this is a problem for objective theories of well-being<sup>61</sup> since the prioritisation of health above knowledge on the objective list disregards the amount of satisfaction the academics would get from having an extension to their library rather than exercise equipment (Griffin, 1986: 51). It is thus claimed that the objective list account is too rigid to account for the nuances in individual lives.

The apparent difficulty of responding to this objection is that the objective list is defined as accounting for well-being independently of the individual’s experiences and desires. However, it is possible for an objective account to take into consideration the variances in individual preference without being reduced to the subject’s preferences, but by being subject-relative. For a theory to be subject-relative means: “...that assessments of an agent’s well-being concern how things are going *for the agent herself*” (Varelius, 2003: 367). The possibility of developing a subject-relative account that focuses on individual

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<sup>61</sup> Griffin’s objection is raised specifically against basic needs accounts of objective well-being, although it is apparent that the same objection could be raised against all types of objective list theory. For instance, a list based on intersubjective agreement or intuition might also rank the preservation of health above the furtherance of knowledge. In the following I use Griffin’s objection in this more general way.

well-being (as opposed to the well-being of humans in general) is not ruled out by the adoption of an objective list account of well-being. Indeed, an objective list theory:

...does not deny that an individual's attitudes may partly determine what is prudentially valuable for her. An individual's attitudes do not determine what items properly belong on her objective list, but among the items that appear, some may include requirements concerning her attitudes and opinions. For example, an objective-list view might well hold that one good thing for an individual is that her important life aims be satisfied, with importance determined by her own subjective ranking of her aims (Arneson, 1999: 117).

Thus, even though an objective list is not reducible to a subject's preferences or desires, this does not mean that an objective list cannot accommodate individual aims, goals, preferences and values. One way in which this could be accommodated would be to include: "...autonomy on one's list, claiming that the informed and reflective living of one's own life for oneself itself constitutes a good" (Crisp, 2008). Significantly, just because autonomy features on the list this does not concede that autonomy should always be respected. Rather, exercising autonomy would be only one element on the list that contributes to overall well-being.

Furthermore, the objective list should also be treated as being relative to circumstantial factors. Imagine, for instance, that Griffin's scholar is in the midst of a heart attack. Given the scholar's preference for furthering her knowledge rather than protecting her health, would it be reasonable to suppose that it is in her best interests to be handed a rare academic text book to read in her last moments rather than to take her to hospital for treatment? The answer to this question is almost certainly no. The solution is thus to defend the position that the items on an objective list can vary from individual to

individual in terms of their personal preferences, but that the relevance of their preferences in determining the ordering of items on the list varies from circumstance to circumstance. Such an account would be independent of the subject's preferences but relative to an individual's tastes and circumstances. The objection that objective list accounts are too rigid cannot be sustained.

## **7.6 CONCLUDING REMARKS:**

At the start of this chapter I explained that supporters of the doctrine of informed consent defend its use on the basis that the competent patient is the best judge of her best interests (section 7.1). The SJS for making decisions on behalf of incompetent patients is based on the same supposition since it supposes that if the patient were competent then she would be the authority as to the medical decision that is most likely to protect or promote her best interests. In order to proceed with my defence of paternalism (chapter 8 and 9) and the justified interference with a patient's medical decision, I explored three types of theories of well-being on the basis that a medical decision that is in a patient's best interests is the one that best protects or promotes her overall well-being.

In this chapter I have defended an objective list theory of well-being (section 7.5) and rejected the hedonic mental state account (section 7.2) and desire satisfaction theories (section 7.3). The hedonic mental state account claims that well-being consists in the individual's pleasurable experiences. This account was presented as providing an impoverished account of well-being in light of Nozick's thought-experiment of the

experience machine (section 7.2.1) and the possibility that pleasurable experiences can often accompany medical decisions that are detrimental to patient health since often medical interventions will be painful (section 7.2.2).

Furthermore, in section 7.3 desire satisfaction accounts of well-being were shown to attempt to account for individual well-being in terms of maximal satisfaction of that individual's desires. This account construed the medical decision that is in the patient's best interests as the one that is most likely to satisfy the patient's desire. Actual desire theories (section 7.3.1), which claimed that the desires that contribute to well-being when satisfied are those that the individual actually has, were found to be unsatisfactory because actual desires can be defective, based on incomplete information, flawed reasoning, faulty concepts, arbitrary factors, and it is possible that the individual never knows whether her desire has been satisfied (section 7.3.2). Informed desire satisfaction theories (section 7.3.3) supposed that the desires that contribute to well-being are those that one would have if one was fully informed. This account was rejected because of the difficulties of determining how much information is needed for a desire to be sufficiently informed, both in terms of the strong reality requirement (section 7.3.4) and the weaker justification requirement (section 7.3.5). Moreover, in section 7.4 I exposed a central difficulty with desire satisfaction accounts, specifically that they must rely on the principle that harm\* always outweighs our everyday conception of harm (see section 5.1). For this reason it is always possible to desire things that, when satisfied, are detrimental to one's own well-being. Unless one adopts the position that harm\* is of greater moral significance than harm when determining well-being, desire satisfaction theories are implausible accounts of individual well-being and patient best interests.

Given the difficulties with these accounts I have adopted an objective list theory of well-being (section 7.5). The objective list theory simply states that the individual's pleasurable experiences or the satisfaction of her desires are not the only thing that contributes to well-being and that: "...the well-being of an agent depend[s] entirely on states of the world apart from the state of mind of the agent whose well-being is under review" (Arneson, 1999: 115). Specifically, I argued that an objective list can be determined intuitively (section 7.5.1) and that the theory can also be subject and context relative (7.5.2). Put in the context of medical decision making the objective list theory of well-being dictates that the medical outcome that is in the patient's best interests is one that protects or improves that patient's objective well-being.

A consequence of the objective list account of well-being is that it is not obvious that a patient is best placed to make a medical decision that protects her best interests since although such an account is subject-relative it identifies the patient's best interests independently of or even contrary to the patient's own desires and/or experience of pain. Items on the objective list may or may not diverge from what the individual desires or with what would bring her the most pleasure in a certain scale of time. Instead, it is contended that well-being: "...consists of the realisation of specific, explicitly normative ideals" (Brock, 1993: 97). For the time being an explicit defence that a medical practitioner is in a better position than the competent patient to make medical decisions that protect that patient's best interests is deferred until section 9.2.3.1 as part of my defence of hard paternalism.

The remaining practical question is how such a theory can be applied when making medical decisions on behalf of patients in order that their overall well-being is maintained or improved. Earlier I defined medical decisions that are in the patient's 'best interests' as those that are most likely to protect or improve the patient's overall well-being. On my account, in order for such decisions to be in the patient's best interests not only must the patient's objective well-being be determined but it must also be worked out which decisions are likely to conform with this account of well-being and thereby actually protect the patient's best interests. However, within the context of this thesis I am unable to develop a full account of objective well-being that can be applied in medical practice. Nor is it plausible to provide an account of what medical decisions are in a patient's best interests in every instance in which it is an issue. The result of this analysis is to highlight that an individual is not automatically the best authority for determining the medical decision that is in her best interests, and therefore that the doctrine of informed consent is an unsuitable means for protecting patient well-being.

## **CHAPTER 8: MEDICAL PATERNALISM**

In chapters 6 and 7 I argued that the absolutist cannot account for the value of exercised free choice in a way that justifies prioritising the doctrine of informed consent over the duty of care. In chapter 6 I argued against the prioritisation of informed consent procedures over the duty of care on the basis of absolute respect for autonomous patient choices. This was achieved by presenting a thought-experiment of the closest possible absolutist world (PAW\*) in which the benefits the absolutist claims her position promotes, including epistemic privilege (6.2.1), therapeutic gain (6.2.2), and objective desirability (6.3.1) were each shown to suffer in the possible world governed by absolute respect for patient autonomy (PAW\*). In chapter 7 I defended an objective list account of well-being which rendered implausible the suggestion that individual is an authority as to the nature of her best interests.

In this chapter I begin to mount a positive defence of hard paternalism – the position that the duty of care should be prioritised over considerations of informed consent. In order to achieve this I present a detailed definition of paternalism (section 8.1) which I then use to make a distinction between soft paternalistic interference with the medical choices of incompetent patients (section 8.2) and hard paternalistic interference with the medical choices of competent patients (section 8.3). After rejecting various theories of hard paternalism present in the literature (section 8.4) I provide a justified account of hard paternalism in Chapter 9.

### **8.1 FORMS OF PATERNALISM**

In this section I provide a definition of paternalism as a basis for my defence of a justified account of hard paternalism in Chapter 9. Whilst my definition largely draws upon the conditions for paternalism presented in Archard (1990), I add a slight modification to his third condition. I subsequently use the modified account of paternalism in order to clarify the distinction between soft (8.2) and hard paternalism (8.3).

A paternalistic act can be broadly defined as the: "...usurpation of decision making, either by preventing people from doing what they have decided or by interfering with the way in which they arrive at their decisions" (Dworkin, 1988: 123). On this simplified understanding, medical paternalism will involve the usurpation of a patient's medical decision or an interference with the patient's process of medical decision making by the medical practitioner.

However, the definition of paternalism must be more rigorous in order to clarify the various ways in which an action can be paternalistic. A successful definition of paternalism must have the means for making a distinction between paternalistic interference with incompetent and competent individuals and the ways in which an individual can be interfered with paternalistically.

Archard's intricate analysis of paternalism provides the basis for a more precise definition. According to Archard, P's behaviour towards Q is paternalistic iff it meets the following three conditions:

- (1) P aims to bring it about that with respect to some state(s) of affairs which concerns Q's good, Q's choice or opportunity to choose is denied or diminished;
  - (2) P's belief that this behaviour promotes Q's [best interests]<sup>62</sup> is the main reason for P's behaviour;
  - (3) P discounts Q's belief that P's behaviour does not promote Q's [best interests]
- (Archard, 1990: 36).

These three conditions are useful for delineating the nature of paternalism. As I will explicate below in more detail, both (1) and (2) provide for an accurate definition of paternalism. However, I argue that (3) is an overly strict constraint on the nature of paternalistic interference. For this reason I reformulate (3) (section 8.1.3) in order to provide a more inclusive definition of paternalism.

### **8.1.1 Condition (1)**

Condition 1 requires that in order for an intervention to be paternalistic an individual, P, must aim to deny or diminish the choices available to an individual, Q, with regard to her best interests. I contend that this condition can be met in three ways. Firstly, P can simply deny Q's choice. In order to clarify how an individual's choice can be denied consider the case in which patient Q must make a decision on the course of treatment she is to take for her breast cancer. Her healthcare provider is able to provide her with (i) surgery, (ii) radiotherapy, (iii) chemotherapy, (iv) hormone therapy, or (v) a combination of the four. Let us suppose that patient Q chooses treatment option (iv).

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<sup>62</sup> I have replaced Archard's use of the term 'good' with 'best interests' in order that the definition of paternalism outlined here remains consistent with the best interests account of well-being I developed in Chapter 7

Patient Q's choice can be straightforwardly denied when the medical practitioner, P, refuses to provide her with the hormone therapy that she has requested.

An alternative way in which condition (1) can be met is through the decreasing of options. Instead of denying the patient the option she chooses, the medical practitioner can simply withhold information regarding the possibility of the option of (iv) hormone therapy from the outset. In such a case the options that Patient Q believes are available to her are reduced from five to four; option (iv) is unknown to her and so not available for her to choose.

As Archard points out, an individual's options can also be decreased by *adding* an option to a choice-set without fully informing an individual of its nature. Consider Archard's case of the 'secret patron':

P believes that Q's having or doing X would be for Q's [best interests]...P makes X freely available to Q intending that Q will choose X. Since P knows that Q would be disposed not to choose X if Q knew P to be its donor, P lies to Q about the source of X (Archard, 1990: 37).

In such a case Q has incomplete information as to the nature of X. Since Q would not have chosen X if she knew P to be its donor she is unable to freely choose from the options available to her. Since P lies to Q about the nature of option X, the options she can freely choose from are paternalistically diminished.

An individual's options can also be paternalistically diminished when an intervener *adds* an 'irresistible' option to her choice-set. Consider a case in which P offers various

options to Q in the knowledge that Q has certain weakness of will that will guarantee that she will choose option X (Archard, 1990:38). Within the context of medical practice, imagine a scenario in which a private doctor, P, has a patient who cannot afford medical treatment. Dr. P is aware of this. When Dr. P makes an option available to her of treatment that is free of charge because it is currently on a research trial he makes her an offer she can't refuse. By including this option in her medical choice-set Dr. P paternalistically decreases the options available to her.<sup>63</sup>

### **8.1.2 Condition (2)**

Condition (2) states that in order for an action to be paternalistic the paternalist must have the correct motivation for interfering with an individual's choice-set. Specifically, she must aim to protect or promote the individual's best interests. Although the demand that paternalistic interference must aim to protect or promote an individual's best interests is widely supported,<sup>64</sup> a clarification to Archard's condition as presented here must be made. Archard connects the paternalistic motivation for interfering with an individual's actions or choices in order to protect her best interests with the usurpation of the individual's own conception of her best interests (Archard, 1990: 41; 1994: 284-5). It is thus assumed that in addition to condition (2), the paternalistic intervention must specifically override: "...the individual's own evaluation of where her own [best interests] lie" (Arneson, 2005: 266).

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<sup>63</sup> The denial or the diminishing of options by itself does not count as paternalism. Although this condition is necessary it is not sufficient and will only constitute paternalism in conjunction with conditions 2 and 3.

<sup>64</sup> For example it has been claimed that: "[i]f A is acting paternalistically toward S, then A must have the good of S, not his own good, as the goal of his action" (Gert and Culver, 1981: 206). Likewise Pellegrino and Thomasma have stated that: "[p]aternalism centres on the notion that the physician...has better insight into the best interests of the patient than does the patient" (Pellegrino and Thomasma, 1988: 7).

However, I shall maintain that an intervention can meet condition (2), without the action or choice usurped being one that the individual regards to be in her best interests. This is because according to the absolutist an individual's choices can be risky or harmful, but remain autonomous (section 3.3). Thus, since autonomous choices can be risky or harmful, interference with an individual's choice can be paternalistic *even if* the choice that is supplanted is not one that the individual regards as being in her best interests. Consider a case in point:

Nihilistic Nikk rejects all forms of medical treatment for his illness because he doesn't see the point of prolonging his existence. Life is meaningless for Nikk. Paternalistic interference with Nikk's decision would not constitute a usurpation of his belief as to the nature of his best interests—Nikk does not see any good in his existence or his non-existence. Rather, in this case, paternalistic interference constitutes the enforcement of *a* conception of his best interests on his refusal to formulate any sort of view of his best interests at all.

My claim that the individual need not have a conception of her best interests in order to be treated paternalistically makes good conceptual sense. Indeed, consider choices an individual makes in the full knowledge that it will harm her best interests; cases of attempted suicide, deciding to take up smoking, or going to the pub when one has a paper to finish writing, are all cases in which an individual makes a decision which the individual is fully aware fails to protect her best interests. Since paternalistic interference need not usurp an individual's conception of her own best interests all that is required of condition (2) is that the interferer supplants an individual's choice for the sake of protecting what she believes to be in the individual's best interests; it is

irrelevant whether the individual regards the choice she wishes to make as potentially harming or furthering her best interests.<sup>65</sup>

### **8.1.3 Condition (3)**

The final condition (3) recognises that in order for an action to be paternalistic the interference must be unwanted by the individual whose choice is interfered with. However, the claim that P must discount Q's *belief* that P's interference does not promote Q's best interests is too strong a condition on paternalistic interference. As shown in section 8.1.1, an individual may be unaware that a paternalistic interference has occurred if she has been given inadequate information as to the number of options available to her in her choice-set or the motives of her paternalist. If it is possible for an individual to be ignorant that she is being treated paternalistically then it follows that it is possible that she does not *believe* that P is interfering with her choices. A preliminary reformulation of condition (3) should follow thusly:

(3\*) P discounts the belief that Q *would* have *if* she were relevantly informed of P's interference with her choices, that P's interference does not promote Q's best interests

However, condition (3\*) is still too strong a constraint on paternalistic interference. This is because, as indicated in section 1.3, it is possible for an individual to knowingly make

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<sup>65</sup> It might be argued that it is always in an individual's best interests to act autonomously. However, it is unclear that individuals always regard the exercise of autonomy to be in their best interests. For example I might not feel expert or trustworthy enough to make a particular choice available to me. For these reasons, the motivation must be to protect and promote an individual's best interests regardless as to whether the decision usurped is believed by the individual to be in her best interests.

a decision that is not in her best interests. In such cases Q may be relevantly informed that P's interference does promote her best interests, but nonetheless reject the interference. Consider the case of Q deciding to take up the habit of smoking. Q is aware that the decision is not in her best interests. When P steals her cigarettes Q recognises that P is acting in her best interests but nonetheless refuses to condone Q's interference with her choice.

What is therefore relevant for paternalistic interference is not Q's belief that P is failing to act in her best interests, but rather that the interference is unwanted and not consented to. We should thus adopt the weaker constraint that:

(3\*\*) P discounts the absence of Q's informed consent or the absence of Q's possible consent if she were to be relevantly informed, of P's interference with her choices.

In conjunction with conditions (1) and (2), condition (3\*\*) provides necessary conditions for paternalistic interference.

## **8.2 SOFT PATERNALISM**

The above definition of paternalism can be further refined into 'soft' and 'hard' formulations. In contrast to the basic definition, soft paternalistic intervention only applies to patients who are incapable of making medical decisions and so does not require the usurpation of decision making. Soft paternalism differs from the above

definition by only being justified when: "...the person for whom we are acting paternalistically is in some way not competent"<sup>66</sup> (Dworkin, 1988: 124). Soft paternalism is defined by Feinberg as encompassing those paternalistic interventions that interfere with an individual's non-voluntary choices, permitting: "...interference only in the absence of voluntariness or genuine consent" (Feinberg, 1986: 15). For this reason Feinberg claims that soft paternalism is anti-paternalistic, in the sense that it does not interfere with the patient's autonomy. An instance where soft paternalistic interference may occur can be adapted from Grisso and Appelbaum:

Suffering from the effects of peripheral vascular disease, a 71-year-old woman, Mrs. B was admitted to the hospital with gangrene of the three middle toes on her left foot. The residents on the surgical unit explained to her the likelihood that, without amputation of the distal part of her foot, the infection would spread, leading either to subsequent amputation of her leg or, if treatment were still withheld, to her death. She was able to recount everything she was told but refused to proceed with the surgery. When the residents asked why, Mrs. B explained that, although she thought the doctors were sincere in their desire to help her, they nevertheless were mistaken about the nature of her condition. Her toes were not gangrenous, but simply dirty. If the nurses would wash her toes, which she herself couldn't reach, they would no longer be black and she could go home. Washing her toes and informing her that they were still black did not change her view of the situation; Mrs. B continued to claim that it was dirt and not gangrene that was the cause of the problem (Grisso and Appelbaum, 1998: 42).

In this example, Mrs. B's inability to recognise that her toes were gangrenous and her consequent inability to make a competent decision regarding her medical treatment could result in courts and medical practitioners proceeding with the amputation without her consent. Since Mrs. B is incompetent and unable to make an autonomous decision then this intervention would constitute a form of soft paternalism.

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<sup>66</sup> The nature of competence and incompetence is explored in Chapter 2.

In light of the definition expounded in section 7.2.3 the only conditions that soft paternalist intervention need meet are conditions (1) and (2). In terms of condition (1) soft paternalistic interference will diminish an incompetent individual's choice-set by removing her decision altogether; the incompetent individual is denied all options regarding a particular decision because she is incapable of exercising free choice.

Secondly, soft paternalistic intervention meets condition (2) that P believes that his behaviour promotes Q's best interests and that this is the main reason for P's behaviour. However, since soft paternalism does not usurp an individual's decision making process, it does not meet condition (3\*\*) because the individual is unable to consent to the interference. Her incompetence means that she is unable to actually consent to the interference and renders it impossible for her to refuse to consent to the interference because she cannot be relevantly informed.

Significantly, because acts of soft paternalism do not interfere with or usurp a patient's choices then it is difficult to view it as a form of paternalism at all. Indeed, it has been shown that soft paternalist acts do not need to meet condition (3) and that condition (1) is completely met because all choice and options are denied to the individual. Since soft paternalism is only applicable to patients who are incapable of making decisions about their medical treatment, making decisions for them is: "...really no kind of paternalism at all" (Feinberg, 1986: 16). Gert and Culver explicitly deny that soft paternalism is a form of paternalism because: "...we cannot act paternalistically toward someone whom we do not regard as believing that he knows what is for his own good" (Gert and Culver, 1981: 210). In fact, soft paternalism could be viewed as *anti*-paternalistic in the sense that it:

“...permits interference only in the absence of voluntariness or genuine consent” (Feinberg, 1986: 15). Rather than strictly being form of paternalism, soft paternalism can *instead* provide a means for determining what is to be done with patients who are incompetent.

### **8.3 HARD PATERNALISM**

Differing from soft paternalism, hard paternalistic interventions are those that interfere with or ignore the decisions of *competent* persons who are capable of making decisions for themselves (Feinberg, 1986: 12). In the domain of medical decision making hard paternalism may be invoked if the competent patient’s decision is highly risky or likely to cause harm. In such cases, a clinician or court may judge: “...that a patient’s choice, while competently made, is so flagrantly antithetical to his own welfare that the choice must be ignored and the patient’s protests or objections overridden” (White,1994: 33). In order to make evident the difference between soft and hard paternalism it is instructive to adopt another example from Grisso and Appelbaum:

Seven years after an initial diagnosis of and surgery for breast cancer, a 43-year-old woman, Miss. C., began having neck stiffness and tingling in her arm. A chiropractor took cervical spine films, which revealed a compression fracture, and a subsequent MRI showed multiple cervical spine metastases. At least one of the masses appeared to be impinging on the spinal cord. The nature of her problem was explained to her, including the possibility of quadriplegia, respiratory paralysis, and even death without rapid treatment. She was told that immediate treatment with intravenous steroids plus radiation therapy was likely to be effective over a period of days. Although she clearly understood what she was told, the patient declined any further medical treatment. She told a psychiatric consultant that she wanted to go home, because *the power of faith was the best way to care for her problem*. Accepting any medical treatment would be giving in to fear and would interfere with the spiritual healing. Further probing revealed that the patient had, over the past several years, become active in a

religious group that emphasized the power of spiritual healing and had consistently adhered to their doctrines (Grisso and Appelbaum, 1998: 47-8)<sup>67</sup>

This example differs from the example of Mrs. B because the woman concerned is fully aware that she needs treatment; the reason why Miss. C refuses to have the recommended treatment is not because she is incapable of making a decision, but rather because she believes that the best way to secure her health is through religious faith. Assuming that Miss. C is competent to make her decision then to go ahead with the proposed treatment against her wishes would constitute an instance of hard paternalism.

Hard paternalism meets all three conditions of the definition of paternalism. Similarly to soft paternalistic interventions hard paternalistic interventions must meet condition (2); the main motivation for the hard paternalist's interference must be the belief that her interference protects or promotes the individual's best interests. Likewise, on the hard paternalistic account condition (1) can also be met because the competent individual has a choice-set which she is able to choose from for herself. Interference with these choices will be paternalistic in the hard sense when the paternalist aims to deny or diminish the choices available to the individual. In addition, condition (3\*\*) is met because the competent individual is able to offer or refuse her consent to the paternalist's interference. When P discounts the absence of competent Q's consent then, in conjunction with conditions (1) and (2), she treats her paternalistically in the hard sense.

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<sup>67</sup> It might seem odd that Miss C. sought medical help only in order to reject it – this is just an incompleteness of the example. For instance, further background could indicate that she was taken for tests as an emergency, or she simply wanted to know the nature of her illness in order to pray for the right healing.

#### **8.4 THEORIES OF JUSTIFIED HARD PATERNALISM**

An adequate justification for hard paternalism is important in the context of the broader aim of my thesis to resolve the tension between protecting patient best interests (under the duty of care) in medical practice and respecting their exercisable free choices as required by the doctrine of informed consent. In this section I explore some attempts to justify hard paternalistic interference where a patient's best interests come into conflict with her exercised free choice. I analyse and reject them in light of my definition of hard paternalism:

- (1)** P aims to bring it about that with respect to some state(s) of affairs which concerns Q's best interests, Q's choice or opportunity to choose is denied or diminished;
- (2)** P's belief that this behaviour promotes Q's best interest is the main reason for P's behaviour;
- (3\*\*)** P discounts the absence of Q's informed consent or the absence of Q's possible consent if she were to be relevantly informed of P's interference with her choices.

Various theories have been put forward to justify hard paternalistic action. I shall analyse four theories presented by VanDeVeer (1986), all four of which I shall reject; the principle of subsequent consent (PSC), the principle of hypothetical individualised consent (PHIC), and the principle of hypothetical rational consent (PHRC) and the principle of autonomy respecting paternalism (PARP). I critique these theories because they all rely on a principle of either actual or hypothetical retroactive consent. For this

reason, each of the theories fail to meet condition (3\*\*) which I have shown to be essential to hard paternalistic interference.

#### **8.4.1 The Principle of Subsequent Consent (PSC)**

The hard paternalist wishing to defend PSC argues that hard paternalistic intervention is only justified when the individual later consents to the interference. According to PSC:

P's paternalistic interference, X, with Q is justified if Q will subsequently consent to P's having done X and P's Xing involves no wrong to those other than P or Q (VanDeVeer, 1986: 67).

On PSC a hard paternalistic intervention is justified when the individual later consents *and* the intervention wrongs no others, and unjustified if the individual fails to subsequently consent or the intervention wrongs others aside from the individual or the paternalist.

There is some intuitive support for PSC. As VanDeVeer illustrates:

...suppose, due to an accident, you received third degree burns over most of your body; at the time you wished to die and opposed any life-sustaining efforts. Still, they were imposed on you. Later you are positively disposed toward the imposition of such treatment. Such cases may tempt us to think that some cases of paternalistic intervention are justified because the subject, at a time *posterior* to the interference, *consents* to the interference (VanDeVeer, 1986: 67)

Thus, on PSC, the act of hard paternalism *becomes justified* at some point after the intervention if the individual consents to the past interference with her choices to it on later reflection.

VanDeVeer notes that PSC is problematic for four reasons and so fails to justify hard paternalistic intervention. These four reasons consist of:

- (i) the nature of the paternalistic interference guarantees her subsequent consent
- (ii) PSC is open to abuse from overly optimistic paternalists
- (iii) The epistemological difficulty of predicting subsequent consent
- (iv) Ethical difficulties of retrospective justification

I argue that the first two objections can be avoided by the defender of PSC, whilst the latter two objections are sufficient to show that PSC fails as a justification for hard paternalistic interference.

Firstly, VanDeVeer argues that there may be certain cases of paternalistic intervention which *guarantee* that the individual will consent at a later date. As he notes: “[i]n certain cases of brain surgery, indoctrination, or psychotherapy, belated approval may be a by-product of the intervention itself” (VanDeVeer, 1986: 70).<sup>68</sup> VanDeVeer thus suggests that reliance on subsequent consent is insufficient to justify paternalistic intervention, since the way in which the individual’s future consent was formed might also have been interfered with by the paternalist.

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<sup>68</sup> Such an example can be expanded to include instances of ‘Stockholm Syndrome’ with an abused victim subsequently consenting to the abuse she received from her abuser because she now views it as an act of compassion.

However, VanDeVeer fails to note that this problem does not threaten PSC if we add the caveat that subsequent consent only justifies the past paternalistic interference when the consent itself has not been interfered with. On this interpretation, all that the defender of PSC needs is to make a distinction between hard paternalistic intervention which is justified by *autonomous* subsequent consent, and those interventions through which the individual is indoctrinated or coerced to subsequently consent. Although this is unlikely to be an easy task, the defender of PSC has room to argue that the latter situation does not involve an instance of *justified* hard paternalism.

The second problem that VanDeVeer raises against PSC is that it is potentially open to abuse from overly optimistic paternalists. VanDeVeer claims that paternalists could be far too hopeful about the likelihood of the individual offering her consent at a later date (VanDeVeer, 1986: 68). PSC is thus at risk of being abused by the hard paternalist who attempts to justify her paternalistic intervention by relying on the assumption that the individual will share her view on the matter at a later date. VanDeVeer thinks that PSC should thus be rejected on the basis that the theory could be abused by egocentric hard paternalists who paternalistically intervene with an individual even though subsequent consent is in fact unlikely to be forthcoming.

However, once again this objection does not threaten the PSC and simply calls for further clarification. If the hard paternalist can show that she is not basing the likelihood of future consent on facts about her own preferences and values, then she will be able to defend her intervention on the basis of PSC. By adding the further caveat to PSC that the

paternalist judges the likelihood of subsequent consent from an unbiased standpoint the defender of PSC can avoid VanDeVeer's objection that the position is open to abuse.

Despite the failure of the above two objections to PSC, there are nonetheless two insurmountable objections that VanDeVeer correctly raises against PSC. Firstly, there is an insoluble epistemological difficulty of predicting whether or not subsequent consent will be forthcoming; whether the individual will *in fact* consent to the intervention at some future time is epistemologically opaque at any present moment. According to VanDeVeer this is partly because the individual's subsequent consent will depend upon the preferences and attitudes she has in the future, which may have changed from her current preferences and attitudes (VanDeVeer, 1986: 68). Although this argument is correct, VanDeVeer's presentation of the epistemological difficulty is too weak. Not only is it impossible to guess the preferences and attitudes the individual will have at a later date and so estimate whether or not she will consent, in fact it is impossible to guess whether or not the individual will consent *even if* the paternalist had all the relevant information regarding the individual's future preferences and attitudes. The *actual* future consent of the individual is epistemologically inaccessible.

Furthermore, whether or not the individual is in fact *able* to offer consent in the future is also unknowable at the point of intervention. As VanDeVeer suggests: "[b]y chance S may be struck down by lightning or, more likely, an automobile. If so, no subsequent consent will be forthcoming" (VanDeVeer, 1986: 68). Indeed, not only is it possible for the individual to be unexpectedly killed, but the individual could simply leave the country, refusing to have contact with the paternalist or lose all memory of the

intervention taking place. VanDeVeer is thus correct to argue that PSC cannot offer a justification for hard paternalism because it depends upon unknowable facts about whether the future individual will offer her consent. At the point of the hard paternalistic intervention, the paternalist is not in a position to know whether the individual will in fact consent to the intervention or not and so is unable to assess whether or not her paternalistic intervention is justified.

An equally strong objection to PSC is that even if the individual does subsequently consent to the earlier paternalistic interference it is difficult to understand how an action can become justified retroactively. Indeed, if the paternalistic intervention against S is unjustified and so immoral at  $T_1$ , how is it that S's subsequent consent at  $T_2$  changes the moral status of the intervention at  $T_1$ , making it both moral and justified? As VanDeVeer rightly notes: "[i]t is difficult to understand how subsequent consent is supposed to 'reach back in time,' perhaps a considerable segment of time, and legitimize the past act" (VanDeVeer, 1986: 69).

In order to clarify the peculiarity of claiming that past acts can be justified by future consent imagine a situation in which you have been let down by a potential partner. Let us suppose that one evening you have arranged to meet your date, who doesn't show up. Devastated, you are forced to spend the evening on your own, in which time you finish an important document. Although at the start of the evening you are angry with your date, by the end of the night you feel relieved that you had a chance to finish your work and so pleased that your date let you down. However, it would be odd to suggest that at this point you retroactively consent for your date to fail to keep the date. What seems

more fitting is that you recognise a beneficial outcome of your date's failure. You might even go so far as to forgive your date, but to suggest that you *consent* to the situation would be inappropriate. As VanDeVeer notes: "[f]orgiving a wrong...or recognizing a beneficial effect of a wrong done, does not obviously alter the fact that a wrong was committed" (VanDeVeer, 1986: 69-70). Indeed, although past acts can be *forgiven* or *endorsed*, they cannot be *consented* to. Since PSC relies on the mistaken principle that past events can be consented to retroactively it fails to offer a justified theory of hard paternalism. Furthermore, even if the paternalist's wager on subsequent consent is successful, the individual's subsequent consent cannot provide the justification for the initial interference with her choices (Archard, 1993: 349-50). Consequently, due to the epistemological opacity of subsequent consent and the impossibility of retroactive consent, PSC fails to justify hard paternalistic intervention.

#### **8.4.2 The Principle of Hypothetical Rational Consent (PHRC)**

PHRC attempts to justify hard paternalistic intervention by hypothesising whether or not the individual would consent at the point of intervention if she had been *fully rational*. The position of PHRC can be defined thusly:

P's paternalistic interference, X, with Q is justified if:

1. Q would consent to P's Xing were Q both fully rational and aware of the relevant circumstances, and
2. P's Xing involves no wrong to those other than P or Q (VanDeVeer, 1986: 71).

P's interference with Q's choice or opportunity to choose is justified if Q would consent to the interference were she to be fully rational. It is argued by Dworkin that less than full rationality at the point of paternalistic intervention is determined by her: "...irrational propensities, deficiencies in cognition and emotional capacities, and avoidable and unavoidable ignorance" (Dworkin, 1988: 124). Circumstances which cause Q's perspective on the intervention to be irrational thus include both faulty reasoning and ignorance of the true nature of the circumstances. According to PHRC hard paternalistic intervention is justified if we can hypothesise that Q would consent to the intervention if her irrational propensities or her ignorance were removed and she could consider the intervention rationally.

A seeming benefit of PHRC is that it avoids the problem of epistemological opacity faced by PSC since the interference is justified on the basis of the *likelihood* that an individual would consent at the point of intervention were she to be fully rational. It therefore bypasses the problem of ascertaining the patient's future values and desires and whether or not she will retroactively consent to the intervention.

Nonetheless, I argue below that there is an unavoidable problem with PHRC. Specifically, it fails to meet condition (3\*\*) which is required for an intervention to be paternalistic. In addition to the failure of PHRC to justify an intervention which can properly be called paternalist, VanDeVeer has argued that PHRC fails on its own terms for two reasons since it is incomplete. Since the main objection to PHRC does not rely on these internal inadequacies I will only address these arguments briefly before mounting my own objection.

The two problems that VanDeVeer attributes to PHRC are that:

- (i) Whether or not a hypothetically fully rational person would consent to an intervention is unknowable since there is no such thing as a fully rational person.
- (ii) PHRC fails to respect the autonomy of ordinary (non-fully rational) competent persons

Firstly, it is unclear what sort of interferences would be found to be acceptable to a 'fully rational individual' since the notion of a 'fully rational person' is purely hypothetical and refers to no actual person (VanDeVeer, 1986: 75). In order for PHRC to work we would need to develop an account of the sorts of things that a rational individual would consent to in any given situation. Without such an account we are unable to make a distinction between interferences that the paternalist personally considers to be rationally acceptable and those that are in fact rationally acceptable.

Secondly, it has been correctly argued that PHRC is too restrictive (VanDeVeer, 1986: 73). As noted in (section 3.3) absolutism regards individuals as competent even if they make imprudent or risky decisions which are less than fully rational. Ordinary competent individuals do not need to make fully rational decisions in order for their decisions to be autonomous. In order for PHRC to justify paternalistic intervention we need an account as to why we should care about rational decisions, and – since paternalistic interference must be done for the sake of protecting or promoting an individual's best interests – how rationality is connected to the protection of best

interests. Thus in order for PHRC to even begin to provide a plausible justification for hard paternalistic interference we are in need of both (i) a theory of rationality, and (ii) the connection between rational decision making and best interests.

Regardless of these inadequacies there remains an incontrovertible problem with PHRC. Namely, that it fails to meet condition (3\*\*) and so cannot strictly justify interventions that are paternalistic. Compare condition (3\*\*) of paternalistic intervention with the conditions of PHRC

(3\*\*) P discounts the absence of Q's informed consent or the absence of Q's possible consent if she were to be relevantly informed of P's interference with her choices.

1. Q would consent to P's Xing were Q both fully rational and aware of the relevant circumstances, and
2. P's Xing involves no wrong to those other than P or Q (VanDeVeer, 1986: 71).

Whilst condition (3\*\*) requires that Q refuses her consent in the hypothetical situation in which she is relevantly informed the supposition of PHRC is that hard paternalistic intervention is justified on the basis that Q *would* offer her consent in the hypothetical situation in which she is relevantly informed. Thus PHRC is at odds with the basic definition of paternalism.

The key problem with PHRC is thus the attempt to justify paternalistic intervention on the premise that the individual would consent to the intervention in hypothetical circumstances. This gets things back to front. To be a hard paternalistic intervention the paternalist must override the exercisable free choices of an individual and discount the absence of her consent. Ultimately, PHRC cannot justify hard paternalistic intervention since it relies upon the individual's (hypothetical) consent which it is supposed to be denying.

#### ***8.4.3 The Principle of Hypothetical Individualised Consent (PHIC)***

PHIC is presented by VanDeVeer as providing a weaker constraint on paternalistic intervention than PHRC because it does not rely upon a full account of the nature of rationality and its connection to best interests. For this reason, PHIC is presented as a more plausible account of justified paternalism. According to PHIC hard paternalism is permissible if the individual is likely to authorise the intervention under less demanding hypothetical circumstances. Thus:

A's paternalistic interference, X, with S is justified if

1. S would validly consent to A's Xing if (a) S were aware of the relevant circumstances; (b) S's normal capacities for deliberation and choice were not substantially impaired; and
2. A's Xing involves no wrong to those other than A or S (VanDeVeer, 1986, 75).

On this conception, paternalistic interference is justified if the individual would consent to the intervention if she were fully aware of the relevant circumstances involving the intervention and she has normal capacities for deliberation. In simpler terms the position claims that paternalistic intervention is justified if the individual would consent were she to be (i) fully informed, and (ii) competent.

There are two key benefits of PHIC. Firstly – as was with the case with PHRC - it avoids the problem faced by PSC of epistemological opacity since the interference is justified on the basis of the *likelihood* of future consent given the individuals current preferences rather than her actual future consent. The inaccessibility of the patient's future desires means that hard paternalistic intervention is justified on the basis that an individual *would* consent to the intervention at the point of intervention were she to be fully informed and competent.

Secondly, PHIC is not as exclusive as PHRC since it: "...does not require us to decide a difficult question, namely, the precise criteria for employing the not entirely transparent concept 'fully rational'" (VanDeVeer, 1986: 75). The predicted probability of retroactive consent on PHIC is drawn from the individual's own desires, values and lifestyle and so can be more straightforwardly predicted (Scoccia, 2008: 359). Thus, according to PHIC hard paternalistic interference is not justified on the basis of whether *a* fully rational individual would consent to the interference, but rather whether the particular individual, given her values and desires, would consent to the interference if she were to be relevantly informed and had all of her cognitive faculties intact.

Nonetheless, I will show that PHIC suffers the same major inadequacy as PHRC in that it attempts to justify the paternalistic dismissal of an individual's consent on the basis that the individual would consent to it under some hypothetical circumstances. Furthermore, PHIC ignores that fact that in order for a paternalistic intervention to be hard the individual must be competent at the point of intervention. PHIC thus fails to justify hard paternalistic intervention because:

- (i) PHIC relies upon the individual's *consent* to the intervention were she to be fully informed.
- (ii) it assumes that the individual is not competent when the paternalistic intervention takes place

The first problem arises because condition (3\*\*) requires that an interference with an individual's choice is paternalistic in the hard sense if the individual's informed consent is absent, or if the individual *would* refuse to offer her consent *if she were to be relevantly informed of P's interference with her choices*. Thus, although hard paternalistic interference is thus concerned with the individual's hypothetical informed consent, what matters in the hypothesis is that the individual's informed consent is absent in order for an interference to constitute hard paternalism; interference is paternalistic in the hard sense if the individual would refuse the interference *even if* she were to be fully informed of its nature. Condition (3\*\*) thus conflicts with the condition of PHIC that in order for paternalistic interference to be justified Q *would* hypothetically consent to the intervention if she were to be relevantly informed.

It is perhaps open to the defender of PHIC to reformulate (3\*\*) to (3I):

**(3I)** P discounts the absence of Q's consent or the absence of Q's possible consent on the basis that Q *would* consent if she were fully informed and competent.

The defender of PHIC could thus claim that condition (3\*\*) is not a condition of paternalism, and in fact an action is paternalistic were the individual to consent to the intervention if she were fully informed and competent.

Nonetheless, this reformulation is problematic for two reasons. Firstly, in order for a paternalistic intervention to count as being *hard* it must interfere with the choices of a competent individual (as was shown in section 8.3). It therefore makes no sense to suppose that the individual would consent to the interference if she were competent, since her refusal of consent is already a competent one. Moreover, if the individual were not competent to make a particular decision then any interference with her choice would constitute soft paternalism. As such, (3I) cannot provide a justification for instances of hard paternalism.

Secondly condition (3I) ignores the claim in section 8.1.3 that an individual's choices can be paternalistically interfered with without her knowledge. Consider once again the case of the secret patron in which:

P believes that Q's having or doing X would be for Q's good...P makes X freely available to Q intending that Q will choose X. Since P knows that Q would be

disposed not to choose X if Q knew P to be its donor, P lies to Q about the source of X (Archard, 1990: 37).

In this case the secret patron does not give Q full information as to the nature of X. However, we know from the case that if Q *were* to be informed about P's interference with her choices she would not choose X. Nonetheless, such a case seems to be paternalistic; P interferes with Q's options in order to promote her best interests. Condition (3I)'s exclusion of such situations goes against the grain of our intuitions about the nature of paternalistic interference. Indeed, if we share the intuition that paternalistic interference is something that is unwanted or not consented to then we should reject the claim of (3I) that paternalistic intervention is justified if Q would consent to it were she fully informed.

Thus, condition (3I) should be rejected for two reasons. Firstly, it ignores the fact that in order for an intervention to be paternalistic in the hard sense the individual must be competent at the point of interference. Secondly, we have good reason to think that an action is not paternalistic if an individual would hypothetically consent to it were she to be fully informed. Since (3I) can be plausibly rejected, and PHIC fails to conform to condition (3\*\*), PHIC fails to justify hard paternalistic intervention.

#### ***8.4.4 The Principle of Autonomy Respecting Paternalism (PARP)***

PARP, as defended by VanDeVeer, provides an additional attempt to justify paternalism. According to PARP paternalistic interference is justified if and only if:

1. P's doing X involves no presumptive wrong toward Q or others
2. P's doing X does not wrong those other than P or Q, and either:
  - a. Q has given currently operative valid consent to P to do X
  - b. Q would validly consent to P's doing X if
    - i. S were aware of the relevant circumstances, and
    - ii. S's normal capacities for deliberation and choice were not impaired

(VanDeVeer, 1986, 88)

Essentially, PARP is a stricter version of PHIC in that it includes the same conditions as PHIC but adds condition 2a - that paternalistic interference is justified if Q has consented to it. Since I have already rejected PHIC I need not spend long rejecting the position.

Firstly, condition 2b should be rejected (as PHIC was in section 7.3.3) on the grounds that hard paternalism does not require the individual to consent were she to be fully informed. On the contrary, in order for an action to be paternalistic the individual must refuse to consent to the intervention since it is only in these circumstances that the doctrine of informed consent will come into conflict with the duty of care. Furthermore, we cannot justify hard paternalism on the basis that the individual would consent to it if she were fully competent since hard paternalistic intervention can only take place if the individual is in a state of competence at the point of intervention.

Secondly, if S has given currently operative valid consent to the intervention then the intervention cannot be counted as paternalistic since in order for the intervention to be

paternalistic her consent must be discounted. PARP straightforwardly fails to provide a justification for hard paternalistic intervention in which consent is not forthcoming.

### **8.5 CONCLUDING REMARKS**

This chapter has developed an account of hard paternalism and thereby provided the groundwork for developing my account of justified hard paternalism in Chapter 9. My final definition of hard paternalism involves three conditions:

- (1) P aims to bring it about that with respect to some state(s) of affairs which concerns Q's best interests, Q's choice or opportunity to choose is denied or diminished;
- (2) P's belief that this behaviour promotes Q's best interest is the main reason for P's behaviour;
- (3\*\*) P discounts the absence of Q's informed consent or the absence of Q's possible consent if she were to be relevantly informed of P's interference with her choices.

On the basis of this definition I analysed instances of soft paternalistic interference with incompetent patient choices as meeting condition (1) and (2). Soft paternalistic interference will thus remove an incompetent patient's choice-set altogether and is justified on the basis that a paternalist reasonably believes that her interference will promote the incompetent patient's best interest (section 8.2). Furthermore, I analysed hard paternalistic interferences as meeting all of the conditions (1), (2) and (3\*\*)

(section 8.3). Unlike soft paternalism, hard paternalism includes condition (3\*\*) since the competent patient is able to offer or refuse informed consent: it is this that the paternalist overrides when she acts hard paternalistically. Given my rejection of current theories of justified hard paternalism in section 8.4 I now turn to providing my own theory of justified hard paternalism in Chapter 9. This final chapter will constitute the final motivation for reversing the current prioritisation of informed consent procedures above ethical considerations surrounding the duty of care.

## CHAPTER 9: REAL HARD PATERNALISM

Given the failings of PSC (8.4.1), PHRC (8.4.2), PHIC (8.4.3) and PARP (8.4.4) I shall provide in this chapter a justified account of hard paternalism in line with the definition I outlined in section 8.3. In order for an action to be paternalistic in the hard sense I proposed there that it must be consistent with conditions:

- (1) P aims to bring it about that with respect to some state(s) of affairs which concerns Q's best interests, Q's choice or opportunity to choose is denied or diminished;
- (2) P's belief that this behaviour promotes Q's best interests is the main reason for P's behaviour;
- (3\*\*) P discounts the absence of Q's informed consent or the absence of Q's possible consent if she were to be relevantly informed of P's interference with her choices.

A justification for hard paternalism cannot contradict any of these conditions in order for it to constitute a justification of *hard* paternalism.

My justification for hard paternalistic interferences will draw upon my developed account of objective well-being in section 7.5. In section 7.1 I thus argue that paternalistic interference is justified when the paternalist interferes with the individual's exercisable free choice on the grounds that her exercised free choice is not in her best interests. In section 9.2 I will deal with a plurality of anti-paternalist

objections to hard paternalism and upon their rejection conclude that my theory of hard paternalism is justified in medical practice – thereby resolving the moral tension between the duty of care and respect for patient autonomy in favour of prioritising the duty of care (section 9.3).

### **9.1 THE BEST INTERESTS ACCOUNT OF HARD PATERNALISM**

The main point of contention thus far regarding the justification of hard paternalistic interference has been condition (3\*\*) and the circumstances in which it is justifiable to override an individual's actual or hypothetical informed consent. It has been shown that any appeals to the individual's subsequent or hypothetical consent (sections 8.4.1-8.4.4) provide inadequate justifications for hard paternalism since they are contradictory to condition (3\*\*).

If consent is irrelevant then we need another moral property by which to govern whether or not a particular instance of hard paternalistic interference is justified. In this section I defend the thesis that hard paternalistic intervention is sanctioned when, in line with condition (3\*\*), P discounts the absence of Q's informed consent or the absence of Q's possible consent *on the basis that Q's refusal to consent is not in her best interests*. Thus, on my account, hard paternalistic intervention is justified iff:

- (1) P aims to bring it about that with respect to some state(s) of affairs which concerns Q's best interests, Q's choice or opportunity to choose is denied or diminished;

(2) P's belief that this behaviour promotes Q's best interests is the main reason for P's behaviour;

(3\*\*) P discounts the absence of Q's informed consent or the absence of Q's possible consent if she were to be relevantly informed of P's interference with her choices on the condition that:

a) Q's choice is detrimental to her best interests.

I shall term this theory of justified hard paternalism the Best interests Account (BIA). Importantly in order to know whether hard paternalistic intervention is justified on BIA in terms of condition (3\*\*):a) and (2) the intervener needs to have very strong grounds for believing that (a) the patient's choice is in some way detrimental to her objective best interests, and (b) that what she chooses for the patient despite their contrary choice is the course of action required to promote her best interests. This is because the paternalist will not be justified in acting paternalistically if she has an unsupported or crazy belief about the nature of Q's best interests. For the remainder of chapter, an implicit condition of justified hard paternalism will be that P's belief about Q's best interests will be *reasonable*.

Hard paternalistic interference can be shown to be justified on the basis of protecting individual best interests by drawing upon my defence of an account of an objective theory of best interests in chapter 7. My objective account of best interests thus not only undermines the prioritisation of informed consent procedures in medical practice but also provides a basis on which to judge whether or not a competent individual's choice fails to contribute to her best interests.

## **9.2 OBJECTIONS TO HARD PATERNALISM**

In order for BIA to count as a credible justification for hard paternalistic interference it is necessary to answer possible objections to the theory. The task of defending BIA against possible objections is made difficult by the negative connotations associated with the term: 'paternalism'. As Feinberg notes, the notion of paternalism is presumptively derogatory: "...and thus tends to be tendentious and question-begging in its bare application" (Feinberg, 1986: 4). The *intuition* that hard paternalistic interference is morally bad should be noted as implicit in VanDeVeer's description of a paternalistic interference as one in which we: "...foist our conception of their good" (VanDeVeer, 1986: 424 *emphasis added*) upon another individual. To 'foist' something upon someone is already to impose something upon them *without warrant*. VanDeVeer's description of what is commonly understood as paternalism thus already implies that it is unjustified.

A negative intuition associated with hard paternalism is that such interferences are 'infantilizing'. The 'infantilizing' intuition claims that in instances of hard paternalism, P stands in a relationship with Q: "...as a parent (or perhaps a male parent!) stands to his children, and that normal adults might properly be treated as if they were children" (Feinberg, 1986: 4). The relationship between the hard paternalist (P) and the individual (Q), is thus compared with the relationship between a parent and child. As De Marneffe notes, hard paternalism initially seems repugnant because: "[i]n limiting our liberty for our own good, it seems that the government treats us like children" (De Marneffe, 2006: 68). The treatment of competent adults as though they were children is regarded to be intuitively morally abhorrent.

It has been suggested by De Marneffe that the analogy between hard paternalistic relationships and parental relationships is weakened by the fact that not all paternalistic interferences can be straightforwardly seen as treating a competent adult as though she were a child, claiming that the infantilizing intuition varies with the significance of hard paternalistic interference. (De Marneffe, 2006: 68). According to De Marneffe, significant hard paternalistic interferences include those which interfere with choices such as whom to marry, or whether or not to reproduce or the direction of one's career which are likely to be significant to the individual concerned. In a medical context we could expand this list to include consent to a hysterectomy or an amputation. Interference with these choices is seen to be infantilizing. Hard paternalistic interference with choices such as whether to drive with a seatbelt, smoking, or eating foods that are high in saturated fat are viewed as less significant and so should not be viewed as infantilizing. Nonetheless, the intuition that hard paternalistic interferences are *infantilizing* does not hinge on the nature or significance of the interference, but is rather an intuition that it is the very act of interfering with or ignoring the competent individual's consent that is infantilizing. For this reason, De Marneffe's distinction between 'significant' and 'insignificant' choices fails to engage with the intuition.

Nonetheless, such intuitions are not strong enough to undermine the justification for hard paternalistic intervention, since whether or not one has the intuition can simply be seen as a marker of the dispute between the hard paternalist and absolutist.<sup>69</sup> Importantly, unless negative presumptions associated with paternalism are theoretically

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<sup>69</sup> For instance, intuitions that hard paternalistic interventions are 'infantilizing' can be equally described as ones that are 'protecting' or 'caring'. We should thus be wary of the connotations that arise relating to a certain description of paternalistic intervention.

founded then they tell us little about the moral status of hard paternalistic intervention. For this reason, any distaste toward hard paternalism must be theoretically grounded in order to undermine justifications for hard paternalism such as BIA. One way in which intuitions of distaste may arise is from an implicit adoption of absolutism about respect for exercisable free choice; when respect for free choice is viewed as sacrosanct, any hard paternalistic interference with an individual's choices will appear to be morally repugnant. However, given that I have argued against absolutism about free choice (Chapter 4) I will not be exploring absolutist objections to hard paternalistic interference in this section. Specifically, the evaluation of absolutism in terms of PAW\* showed that that it is unreasonable to maintain that the value of respecting free choice always outweighs other moral considerations. This renders absolutist objections to hard paternalism inappropriate.

In this section I instead address objections to BIA which claim that hard paternalism cannot be justified on its own terms. Leaving aside negative connotations associated with hard paternalism, I shall address two objections to hard paternalism which do not rely upon a presumption of absolutism. I shall refer to these objections as:

### **9.2.2 The Unlikelihood Argument**

### **9.2.3 The Incoherence Argument**

Before mounting my attack against these objections I provide an analysis of what counts as unjustified hard paternalistic interference on BIA, below.

### 9.2.1 Unjustified Hard Paternalism

In order for the unlikelihood (8.2.2) and incoherence (8.2.3) objections to have force against BIA it must be shown that the adoption of BIA is prone to lead to instances of unjustified hard paternalism. It is therefore essential to present a detailed account of the nature of unjustified hard paternalism. According to BIA, P's hard paternalistic interference with Q is justified if it meets condition **(a)**:

**(a)** Q's choice is detrimental to her best interests

Accordingly, P's hard paternalistic interference with Q's choice will be *unjustified* if it fails to meet condition **(a)**, i.e. if Q's choice is not detrimental to her objective best interests.<sup>70</sup> Note that in order for the interference to constitute hard paternalism, the interference must also meet conditions **(1)**-**(3\*\*)** of BIA. This constraint is particularly pertinent in light of condition **(2)**:

**(2)** P's belief that this behaviour promotes Q's best interests is the main reason for P's behaviour

Thus, for a paternalistic interference to be both *hard* and *unjustified*, it must meet condition **(2)** but fail to meet condition **(a)**; in other words, P must be motivated to protect Q's best interests but be unresponsive to the fact that Q's choice is itself in Q's best interests. There are two ways in which it could be the case that P fails to acknowledge that Q's choice is in Q's best interests. One way in which this could be the

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<sup>70</sup> This condition covers Q's hypothetical or possible choice if her actual choice has not been made.

case is if (i) P falsely believes that Q's choice is detrimental to Q's best interests. In such cases P will interfere with Q's choice because she mistakenly believes that respecting Q's choice is harmful to Q. For example, consider a case in medical decision making in which:

Patient (Q) goes to her doctor (P) seeking help for her depression. Q decides that she wants to be treated with a course of medication. P believes that Q's decision to take medication for her treatment is not in Q's best interests because Q has a history of drug abuse. Since the medication required to treat Q's depression is highly addictive P refuses to respect Q's decision and instead forces her to take a course of psychotherapy. By (hard) paternalistically forcing this treatment upon her, P is motivated to protect Q's best interests. P's actions thereby constitute an act of hard paternalism.

However, imagine that P's belief that Q's choice of medication would be detrimental to Q's best interests is false. In fact, psychotherapy would be ineffective for Q. Thus, although medication would be a risky option given Q's history, this option is in Q's best interests. In this case, P's hard paternalistic interference with Q would be unjustified because P falsely believes that Q's choice is not in her best interests.<sup>71</sup>

Secondly, P can fail to acknowledge that Q's choice is in Q's best interests when (ii) P *ignores* the fact that Q's choice is in her best interests. In order to grasp this second form of unjustified hard paternalism recall that it is possible for there to be a plurality of things that are in the individual's best interests since there are a number of items on an objective list account of well-being (section 7.5). P's interference with Q might bring about a situation that is in Q's best interests even though respecting Q's choice would

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<sup>71</sup> It is possible that neither P nor Q know what is in Q's best interests and the fact that Q's selection of medication happens to be in her best interests is a matter of chance. However, this does not mean that P's paternalistic interference with Q's choice is justified, since whether or not Q is right, P has failed assess her choices as contributing or detracting from her best interests.

equally be in Q's best interests. A hard paternalistic interference could thus fail to meet condition **(a)**, and thereby be unjustified, if P *ignores* the fact that Q's choice is in her best interests.

In order to clarify the second way in which P could fail to meet condition **(a)** another example can be taken from medical decision making. Consider a situation in which two treatment options are equally in a patient's best interests:

Patient (Q) has made an appointment with her doctor (P) in order to decide upon a form of contraception. Q has decided that she would like a contraceptive implant. P agrees that having the implant would be in Q's best interests; nonetheless she refuses to provide her with anything but an IUD. Both the implant and the IUD are equally effective contraceptive methods, and the difference in the invasiveness of each procedure does not concern Q. Nonetheless, Q does not want the IUD, preferring the implant. When P forces Q to have the IUD her hard paternalistic interference is unjustified since she knowingly overrides the choice made by Q that P is aware is equally in Q's best interests.

Admittedly this is a very odd situation: it is unclear why a hard paternalist would override an individual's choice that protects her best interests, in order to protect that individual's best interests. Nonetheless, it remains a possible scenario of unjustified hard paternalism and so must be addressed when assessing the unlikelihood and incoherence arguments against BIA.

In the following section I will be considering unlikelihood arguments in light of the above definitions of unjustified hard paternalism. In order for P's hard paternalistic interference with Q to be unjustified, P must either (i) have a poorly supported belief that Q's choice is detrimental to her best interests, or (ii) ignore the fact that Q's choice is

in her best interests. However, as I will show, arguments from unlikelihood fail to show that the implementation of BIA will lead to one of these outcomes.

### **9.2.2 The Unlikelihood Argument**

The unlikelihood argument claims that although hard paternalistic behaviour can be justified in *some* instances, it is highly unlikely that *all* acts of hard paternalism will be justified in practice. It is maintained that, whenever the paternalist interferes with the individual's decision: "...the odds are that [she] interferes wrongly, and in the wrong place" (Mill, 2008: 92). Consequently, in order to prevent cases of unjustified hard paternalistic interferences, it is suggested that *all* hard paternalistic interferences should be forbidden

Arguments from unlikelihood can take different forms. Here I shall evaluate and reject two versions of the argument. Firstly, the epistemic unlikelihood argument (9.2.3), and secondly the slippery slope unlikelihood argument (9.2.4). The Epistemic Unlikelihood Argument claims that if P is at an epistemic disadvantage, her judgement as to whether Q's choice is in Q's best interests is likely to be wrong. The Slippery Slope Unlikelihood Argument claims that permitting instances of justified hard paternalism will lead us down a slippery slope to permitting instances of unjustified paternalism. It is therefore supposed that it is unlikely that the adoption of BIA will ensure that hard paternalistic interferences will be justified. In order for BIA to be prone to these unlikelihood arguments it thus must be shown that more often than not hard paternalistic interference will be unjustified (in sense (i) or (ii)) either because of epistemic or slippery slope considerations.

### 9.2.3 The Epistemic Unlikelihood Argument

It has been argued it is unlikely that a given hard paternalistic interference will be justified because the interferer (P) is in a poor epistemic position to know the content of an individual's (Q) best interests. I have argued that one way in which hard paternalistic interference can be unjustified is if it fails to meet condition **(a)** of BIA when (i) P falsely believes that Q's choice is detrimental to Q's best interests.<sup>72</sup> If, as the anti-hard paternalist claims, P is at an epistemic disadvantage, then it is unlikely that she will know the content of Q's best interests. For this reason paternalistic interferences will often be unjustified according to the epistemic unlikelyhood argument.

In order to maintain that P is epistemically ill-placed to determine Q's best interests, one must assume that the Q is better placed to determine her best interests than P. The unlikelyhood argument would be ineffective if Q is equally well-placed as P to determine her best interests since if this were to be the case then P would be just as likely to determine Q's best interests as Q is herself. The concern that the adoption of BIA would probably lead to instances of unjustified hard paternalism is only outweighed by Q's inability to protect her best interests herself.<sup>73</sup>

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<sup>72</sup> Note that only the first way in which a hard paternalistic interference can be unjustified ((i) P falsely believes that Q's choice is detrimental to her best interest) is vulnerable to the epistemic condition. The second way in which a hard paternalistic interference can be unjustified ((ii) P ignores the fact that Q's choice is in her best interests) is not vulnerable to the epistemic condition, since it depends upon the fact that P *knows* what is in Q's best interests.

<sup>73</sup> It might be contended that even if both P and Q are equally placed to determine Q's best interests, there is still a moral significance when Q chooses for herself. However, given that I have already argued that the value of Q's free choice is limited to choices that are beneficial to Q we should regard P and Q to be on an equal moral footing to make choices for Q when they have an equal knowledge of the content of Q's best interests.

Furthermore, the unlikelihood argument will not work if Q is *worse* placed to determine her best interests. In this case the unlikelihood argument would be irrelevant since it would mean that even if P is very bad at determining Q's best interests P is more likely to protect Q's best interests than Q herself. As Archard notes, in order for the claim that the individual knows her own good better than anyone else to be justified, the individual must be somehow better placed epistemically (Archard, 1994: 285). Taken from the perspective of P's epistemic position, the unlikelihood argument thus relies on Q being better placed than P to determine Q's best interests. If Q is better placed epistemically then it is argued that it is unlikely that P will protect Q's best interests when she paternalistically interferes with Q's choices. For this reason, the conditions of BIA cannot be met and so paternalistic intervention is likely to be unjustified in practice.

In order to undermine the epistemic unlikelihood argument I argue that Q is not always<sup>74</sup> better placed than P to know her objective best interests. Firstly, I run through arguments against epistemic privilege raised in section 6.2.1 contextualising them in terms of the individual's knowledge of her objective best interests; whereas previously I rejected epistemic privilege with regard to satisfying one's preferences for treatment, in this section I utilise the same arguments to reject epistemic privilege with regard to objective best interests which do not depend on whether or not the individual in fact desires the options she is presented with. In addition, I further object to the claim that Q

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<sup>74</sup> Significantly, my account allows that there may be occasions where Q is better placed than P to know the option that is in her best interests. This is supported by my defence of an objective list account of well-being in chapter 7 which included freedom as an objective good to be balanced against other items on the list. I contend that such situations will arise when there are multiple options which when chosen by the patient will equally contribute to that patient's best-interests. In cases such as this it will be in Q's best-interests to make the medical decision for herself. In order to focus on the justification for hard paternalism the following discussion leaves such situations to one side.

is best placed to know her best interests for the reason that her closeness to the outcome of her decisions distorts her perception of the harmfulness of them. For these reasons, I contend that Q is not always better placed than P to know her objective best interests. Consequently, the epistemic unlikelyhood argument against BIA can be rejected.

### ***9.2.3.1 Epistemic Privilege and Objective Best interests***

In section 6.2.1 I argued that individuals do not have an epistemic privilege with choices that are most likely to protect the values they judge to be most important. This was firstly because there are many cases in which an individual does not know, or does not have, a preference with regard to a particular choice-set. Secondly, I argued that the communication of relevant information to aid in patient decision making is unlikely to be successful. For this reason, absolutism about respect for free choice was rejected since an individual's free medical decisions were unlikely to protect her preferences and desires.

In order to argue against the contention that an individual is epistemically privileged with regard to her objective best interests these arguments need to be re-run, but instead of arguing that the individual is not epistemically privileged with regard to the treatment options that best satisfy her preferences, I will argue that she is not epistemically privileged with regard to her objective best interests which do not depend on her preferences.

Given that an individual's objective best interests are not dependent upon her subjective values and desires there appears to be no prima facie reason why she would be better placed to know the content of her objective best interests. Indeed, given my defence of an objective account of best interests, the onus is on the absolutist to explain why the patient is better placed than the medical paternalist to know what treatment option will best protect her objective best interests.

One reason given in support of the contention that Q is best placed to know her objective best interests is that Q is the individual most concerned with protecting her best interests. As Mill contends:

[h]e is the person most interested in his own well-being: the interest which any other person, except in cases of strong personal attachment, can have in it, is trifling, compared with that which he himself has; the interest which society has in him individually (except as to his conduct to others) is fractional, and altogether indirect (Mill, 2008: 84-5).

There is some weight to the claim that the individual knows her best interests better than any other individual because she is the individual that is directly affected by the outcome of her choices. The risk of making a decision that harms Q's interests is more pressing for Q since she is the individual at risk of being harmed.

However, the inference between the claim that Q is most concerned with her best interests to the claim that Q is best-placed to know what constitutes her objective best interests is invalid. Even if it is true that Q is the person most concerned with her best

interests, it does not follow that she is the best authority as to what constitutes them. In fact, Q's closeness to the outcome of her decision can often distort her knowledge of what is in her best interests thereby making her *worse* placed to know her best interests. Indeed, Archard has correctly argued that the individual's closeness to the outcome of her decisions can affect her decision making in a negative way. He notes that we can be overly-optimistic about our abilities and our future prospects and so:

...we may ignore or understate what others can more clearly see to be in our interests. It is impossibly hard to live in an honest, dispassionate recognition of our own fallibility and shortcomings (Archard, 1994: 286).

Cases in which individuals are overly-optimistic about the outcomes of their choices are prevalent in medical decision making in the evaluation of risk. A study by Lloyd has indicated that patient decision making is distorted by their failure to fully understand the risk of the treatment options available to them:

Carotid endarterectomy (CEA) has been shown to significantly reduce patients' long term risk of stroke, but the operation itself carries a significant stroke risk. It is an interesting treatment to examine because the risks of this treatment and the risks of not undergoing surgery are well understood. Seventy three patients on the waiting list for surgery were surveyed after seeing their vascular surgeon in order to determine their understanding of the risks of stroke as a result of surgery and their risks if they had decided no to go ahead with the operation (56 (77%) responded). The surgeons carefully explained the procedure and gave information to patients regarding the risk of CEA based on the unit's own surgical audit and the results of multicentre trials. Patients' recall of the information they had been given was very poor, and only one could recall all of the risks that he had been told. Estimates of their stroke risk without surgery were hugely variable (range 22-100%, mean 57%, actual risk 22%), and were significantly overestimated. Patients' estimates of stroke risk due to endarterectomy were found to have increased threefold (Lloyd, 2001: i15)

The closeness of the patient to the outcome of the decision has been shown to be a major factor in the distortion of the patient's risk perception. Whilst experts assess risk in terms of statistical hazards (Slovic, 1987: 280): "Patients are more apt to judge risk according to the degree to which they "dread" the unwanted outcome. "Dread," in turn, is determined by the degree to which the outcome is irreversible, potentially lethal, and uncontrollable" (Greene, 2001: 55). It may thus be contended that the individual's closeness to outcomes that are at a small risk of being harmful makes them liable to dread the possible outcome and thereby exaggerate the risk of getting a harmful outcome – even if choosing that option is in fact in their best interests. Consider the case of Ugandans who: "...mistrust injections provided at government health institutions (because they generally mistrust the government)...the use of injections in the country is widespread with people reporting that they prefer to seek medical help from people they know, but who are often untrained" (Lloyd, 2001: i15). In this case, individuals associate a high degree of dread with government health programmes and thereby wrongly minimise the risk of receiving injections from untrained friends at the expense of receiving what is in fact safer medical treatment from the government.

Evidence that individuals are liable to dramatically distort the risk associated with certain choices, because of their closeness to the outcome of their choices, undercuts the claim that individuals are epistemically privileged with regard to the content of their best interests. Archard is correct to argue that an individual's closeness to the outcome of a decision can distort her perception of it, thereby warping her perception of what is in her best interests (Archard, 1994: 286).

Given that Q is not epistemically privileged with regard to choices that protect her best interests we have reason to reject the epistemic unlikelyhood argument. The epistemic unlikelyhood argument relied on the paternalist (P) being in a worse epistemic position than the individual (Q) to determine Q's best interests. If this claim were true than it would be probable that (i) P falsely believes that Q's choice is detrimental to Q's best interests, thereby failing to meet justificatory condition **(a)** of BIA. Given this, it was claimed that it is unlikely that hard paternalistic interventions would be justified.

I have shown that in medical contexts, patients are poorly placed to make medical treatment choices that protect their objective best interests because of their closeness to the outcome of the decision. We thus have reason to suppose that an individual who is not directly affected by the outcome of the decision will be better placed to make the medical treatment decision on behalf of the patient in light of that patient's objective best interests. The advantage that a medical practitioner has over an individual is that she has the medical expertise and knowledge to make it more likely that the treatment option will correspond to the patient's objective best interests. Indeed, the medical practitioner has the expertise to gauge the benefits and risks associated with certain medical treatments. It is thus plausible to suppose that a medical practitioner (P) is equally or better placed than her patient (Q) to know which medical treatment will protect the patient's best interests.

#### ***9.2.4 The Slippery Slope Unlikelihood Argument***

A slippery slope argument can be characterised:

...as a practical argument that claims that permitting an act (or policy) will lead to, or increase the likelihood of, an undesirable state of affairs and that this act (policy) should therefore not be permitted (Spielthener, 2010: 149).

In the context of BIA, the slippery slope argument contends that even if hard paternalistic interferences can be justified, permitting hard paternalistic interferences will lead us down a slippery to slope to allowing hard paternalistic interferences in which P either (i) falsely believes that Q's choice is detrimental to Q's best interests, or (ii) ignores the fact that Q's choice is in Q's best interests.

Furthermore, slippery slope unlikelihood arguments also claim that the implementation of BIA will lead to non-paternalistic interventions. This will be the case when interventions fail to meet condition (2) of BIA:

**(2)** P's belief that this behaviour promotes Q's best interests is the main reason for P's behaviour

Notably, if an interference with an individual's choice fails to meet condition **(2)** then it will not be an instance of hard paternalism. Disconcertingly, this means that the main reason for P's behaviour is *not* that this behaviour promotes Q's best interests. Consequently, it is open to P to have malicious motivations for interfering with Q's choice. Thus, according to the slippery slope unlikelihood argument against BIA it is claimed that although:

...there may indeed be *bona fide* cases where the other does know best [we will not] be able to stop [the intervention] in those cases where others have no warrant for thinking that they know best but merely claim that they do so as a specious reason for behaving paternalistically (Archard, 1994: 286).

Nonetheless, in this section I argue that the slippery slope unlikelihood argument is unsuccessful, either in terms of it leading to failures to meet the justification of hard paternalistic interference, or in terms of it leading to non-paternalistic interferences.

Slippery slope arguments are notorious for being invalid. Spielthener claims that the main reason for this is that slippery slope reasoning is defeasible. Thus, even if the conclusion that hard paternalistic intervention will lead to unjustified hard paternalistic interferences, or non-paternalistic interferences follows from the implementation of BIA: "...it need not follow from a larger set of premises, even if the original premises are included...Considering additional alternatives or new consequences may 'defeat' the argument" (Spielthener, 2010: 154). In order to undermine the slippery slope argument we must draw upon further considerations to object to the worry that implementing BIA will lead to instances of (1) unjustified hard paternalistic interferences, or (2) non-paternalistic interferences.

Firstly, consider the worry that adopting BIA will lead to instances of unjustified hard paternalism. For this to be the case P must either: (i) falsely believe that Q's choice is detrimental to her best interests, or (ii) ignore the fact that Q's choice is in her best interests. However, recall that in order to count as an instance of *unjustified* hard paternalism P's interference must still meet condition **(2)**:

(2) P's belief that this behaviour promotes Q's best interests is the main reason for P's behaviour

Therefore, even if P fails to acknowledge that Q's choice is in her best interests, P's intervention will still be one that is aimed at protecting Q's best interests in order for it to be paternalistic. Thus, whilst it may be odd for a medical practitioner to aim to protect the patient's best interests, without realising that the patient's exercisable free choice is itself in the patient's best interests, so long as the medical practitioner is acting paternalistically the patient's best interests will be protected.

The second version of the slippery slope unlikelihood argument is that the practice of justified hard paternalism will lead to non-paternalistic interferences with patient free choice. As noted, in order for this to be the case the medical practitioner would have to *ignore* the fact that the patient's choice is in her best interest. If the medical practitioner dismisses a patient's free choice despite it being in the patient's best interests then this might be because the medical practitioner wants to interfere with the patient in a malicious, spurious or harmful way. This is a more serious concern for the hard paternalist, since the permissibility of justified hard paternalistic interferences may lead to non-paternalistic, and thereby harmful, interferences with patient free choice.

However, it is reasonable to suppose that cases of non-paternalistic interferences with patient free choices can be avoided through the use of various governance mechanisms and codes of practice. Indeed, many ethical models used within medicine are monitored in just this way. Various safeguards have been put in place to govern the ethics of

biobanking in order to ensure that research carried out on human tissue is of benefit to the public (Widdows, 2011: 87) including the Ethics and Governance Council whose responsibility is to “...ensure that the rights and interests of the donors and the wider public are protected and safeguarded” (Widdows, 2011: 87).

Moreover, as was shown in chapter 1 the doctrine of informed consent was developed through various codes of practice and case law. Concerns that informed consent procedures may be ignored, abused through threats or disrespected are protected by the Nuremberg Code (1949) and the Declaration of Helsinki (2008) and cases in which informed consent has become an issue have been addressed in legal trials discussed throughout this thesis (for examples see Re B (2002), Re C (1994) Re T (1992)).

Given that medical ethics is currently monitored through governance mechanisms, ethical frameworks and legislation it is possible that similar mechanisms can be used to supplement the benefits of adopting hard paternalism in medical practice in terms of protecting patient best interests. Although it is not possible here to develop a strategy for monitoring hard paternalism in medical practice this should not be taken to indicate that such mechanisms are impossible. Thus, although more work needs to be done in order to show that such mechanisms can be developed, in the very least the slippery slope argument is not constitute a knock down argument against adopting practices of hard paternalism.

### **9.2.5 The Incoherence Objection**

A second style of objection raised against proposed accounts of justified hard paternalism is that the very notion of justified hard paternalistic interference is incoherent. The basic position of the incoherence argument is that hard paternalistic intervention will *always* fail to protect the individual's best interests because the intervention is itself harmful. According to this objection, BIA can never be justified because it will always cause more harm to the individual than good.

The incoherence argument runs as follows. For all cases of hard paternalistic interference:

1. P's hard paternalistic interference with Q is justified iff it protects or promotes Q's best interests
2. P's hard paternalistic interference with Q causes harm to Q
3. P's hard paternalistic interference with Q causes Q more harm than good.
4. (Given 3.) P's hard paternalistic interference with Q fails to protect Q's best interests
5. (Given 1. and 4.) P's hard paternalistic interference with Q is unjustified.

It is thus claimed that – paradoxically - the attempt to protect or promote an individual's objective best interests via hard paternalistic interference will always fail to protect her best interests. If this objection is correct then BIA does not succeed in providing a justification for hard paternalism. In the following I will show that the incoherence argument is invalid and thereby that it fails to undermine BIA.

In order for the incoherence argument to successfully undermine BIA it must be shown that paternalistic intervention causes harm to the individual (premise 2), and secondly that the harm caused by the hard paternalistic intervention outweighs any benefit the intervention might provide (premise 3). I shall argue that premise 2 must be reformulated in light of my definition of the harm\* principle in section 5.1. With this more precise formulation in play, I shall argue that premise 3 cannot be sustained: the harm\* of paternalistic intervention does not outweigh any benefit that the intervention might provide. The rejection of premise 3 will consequently lead to the rejection of premise 4 and with it the conclusion of the argument. As such the incoherence argument poses no threat to the justification of hard paternalism presented in BIA.

#### ***9.2.6.1 Reformulating Premise 2***

The starting point for the incoherence argument is that paternalistic intervention is harmful to the individual. In order to assess the truth of this premise we must determine in what way paternalistic intervention could be harmful to the individual. There are two ways in which paternalistic interference might be thought of as harmful to the individual. Either, (a) the outcome of paternalistic interference is harmful to the individual, or (b) the very act of paternalistic interference is itself harmful.

I shall argue that in order for the objection to be directed at acts of hard paternalism the anti-hard paternalist must be thinking of harm to the individual in terms of (b) – that it is the paternalistic interference itself that is harmful to the individual. Any attempt to claim that paternalist interferences are harmful in sense (a) conflicts with the definition

of hard paternalism and therefore it is a misinterpretation of the justification for BIA. Furthermore, interpreting premise 2 of the incoherence argument in terms of (b) the very act of paternalistic interference is itself harmful forces a reinterpretation of the premise in light of the absolutist concept of harm\* developed in section 5.1. With this more precise definition in play the rest of the incoherence argument can be undermined.

To begin with, premise (2): *P's hard paternalistic interference with Q causes harm to Q* cannot be interpreted in terms of (a): *the outcome of paternalistic interference is harmful to the individual*. If premise (2) were to be interpreted in this way then the incoherence objection would contradict the definition of BIA. Recall condition **(2)** of BIA:

**(2)** P's belief that this behaviour promotes Q's best interests is the main reason for P's behaviour

In order for an interference with an individual's choices or actions to constitute hard paternalism, P must *believe* that the interference promotes or protects Q's best interests. If the outcome of hard paternalistic interference is harmful, it cannot be because the paternalistic intervener believes that it is so; the paternalist must believe that she is protecting or promoting Q's best interests.

Notably, condition **(2)** of BIA does not require that P's interference with Q actually succeeds in protecting Q's best interests. It is therefore possible for P to believe that her interference with Q is in Q's best interests when in actual fact it is harmful to Q. However, unless all paternalistic interferers are acting in bad faith, the fact that P must

reasonably believe that she is acting in Q's best interests makes it unlikely that all paternalistic interferences will have a harmful outcome in this sense.

Given that the purported harm of paternalistic intervention is unlikely to be an outcome of the intervention, the 'harmfulness' that is claimed to always arise from paternalistic interference must be intrinsic to the nature of paternalistic interference itself. Thus, in order for premise (2) of the incoherence objection to be true, it must be interpreted in terms of (b): *the very act of paternalistic interference being harmful to Q*.

Absolutists have argued that hard paternalistic intervention is intrinsically harmful to the individual because it usurps the individual's autonomy. Hard paternalism is reckoned to be harmful to the individual for this very reason: by definition, hard paternalistic interference is either actually or hypothetically unwanted by the individual concerned.<sup>75</sup> As such, any unwanted interference with an individual's choices and actions will make the individual's life uncomfortable (Mill, 2008: 88). It is thus claimed that hard paternalistic interference is harmful because the interference is, by definition, unwanted by the individual concerned.

Although the observation that hard paternalism can cause actual discomfort to the individual is correct the sort of harm in play can be very small. In fact, in those cases in which the individual is oblivious to the intervention no actual discomfort will occur.

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<sup>75</sup> In line with BIA, in cases where the individual is unaware that the hard paternalistic interference has occurred, we can assume that she would be uncomfortable with the interference if she were to be made aware of it.

Thus, in order for the incoherence argument to work for all cases of hard paternalism, the anti-paternalist must be concerned with a non-experiential notion of harm.

A non-experiential notion of harm can be used by defenders of absolutism. As noted in section 4.3, the absolutist claims that making free choices is *intrinsically* valuable, regardless of its consequences. Thus *even if* hard paternalistic interference would be a better means of promoting and protecting an individual from choices which undermine her best interests, free choice has a non-instrumental value of its own; it is this sort of value which is harmed\* via paternalistic interference. It is perhaps something like this that VanDeVeer has in mind when he says:

...there is a sense in which 'tragedies are permissible.' Indeed, there is a sense in which some tragedies (outcome-wise) are not 'purely tragic', but in one respect, abstractly desirable (VanDeVeer, 1986: 445).

In order to make sense of VanDeVeer's claim that tragedies (outcome-wise) are not 'purely tragic' we should remember the absolutist's distinction between harm\* and the ordinary conception of harm (section 5.1). According to the absolutist, an individual is harmed\* when her free choices are interfered with or overridden. This explains the problem of paternalism: "...that your choosing it is what makes any action of yours valuable, and, correlatively, that its not being chosen by you deprives your actions of any value" (Archard, 1994: 290). On the absolutist conception of harm\* we can interpret premise 2 in terms of: (c) *the very act of paternalistic interference is harmful\* to Q* with premise 2 of the incoherence argument reinterpreted as:

2\*. P's hard paternalistic interference with Q causes harm\* to Q

This is a good interpretation of premise 2 of the incoherence argument in the straightforward sense that *all* paternalistic interferences will cause harm\* to Q in the sense that Q's choices are usurped by P.

Given the reformulation of premise 2 into premise 2\* the incoherence argument should be presented thusly:

1. P's hard paternalistic interference with Q is justified iff it protects or promotes Q's best interests
- 2\*. P's hard paternalistic interference with Q causes harm\* to Q
- 3\*. The harm\* caused by P's paternalistic interference with Q outweighs any benefits gained by Q
- 4\*. (Given 3\*) P's hard paternalistic interference with Q fails to protect Q's best interests
5. (Given 1. and 4\*.) P's hard paternalistic interference with Q is unjustified.

#### **9.2.6.2 The Falsity of Premise 3\***

Given the reformulation of the incoherence argument, the next step is to assess the truth of premise 3\*. The third premise of the reformulated incoherence argument claims that the harm\* caused by overriding Q's free choice *always* outweighs the benefits gained by Q from hard paternalistic interference. In order for it to be the case that the harm\*

caused by hard paternalistic interference *always* outweighs the goods gained by the individual, we must suppose that free choice is the highest ethical value in such situations, thereby adopting the position of absolutism. This is the stance that VanDeVeer (a purported defender of hard paternalism!) takes. VanDeVeer claims that an individual's free choice should always be respected, since even if her free choice leads to "...pain, impairment, and premature death", the cost of paternalistic interference: "...can be enormous; it can involve the surrender of what makes one's life meaningful, indeed, foregoing the pursuit of one's fundamental conception of the good" (VanDeVeer, 1986: 445). For VanDeVeer, the harm\* of paternalistic interference thus stems from (1) its undermining of the 'meaningfulness' of an individual's life and (2) its prevention of an individual pursuing her 'fundamental conception of the good'.

In response to the second claim I refer to my defence of an objective account of best interests (chapter 7). VanDeVeer's worry that paternalistic interference prevents the individual from pursuing her conception of the good can be quelled by drawing upon the objective account of best interests. Firstly, I have presented arguments that an individual's best interests do not map onto her subjective desires (be they actual or informed) (see sections 7.3 and 7.4). For this reason what the individual thinks is in her best interests need not correspond to what is in her objective best interests.

Moreover, I have argued that a paternalist may be equally, if not better placed to determine and protect or promote the individual's best interests (section 9.2.3.1). Thus, that paternalistic interference overrides what the individual considers to be in her best interests does not mean that the content of the interference is *not* in her best interests,

objectively speaking. VanDeVeer's second claim is thus vulnerable to the objection that BIA serves to protect the individual's best interests.

It is worth noting that it remains open to the absolutist to maintain that the harm\* arising from overriding Q's choice still outweighs any benefits gained from paternalistic interference even if Q is not best placed to know her objective best interests. Indeed, VanDeVeer's first claim that paternalistic interference undermines the 'meaningfulness' of the individual's life might be expressed in terms of the intrinsic value of free choice. However, VanDeVeer's first claim can be rejected by pointing out the failings of accounts of the value of free choice mounted in Chapter 6. Since free choice is only valuable when the choice made is in the individual's best interests, then free choice is not of value in those contexts where hard paternalistic interference is justified (i.e. in those situations where the individual's choice is detrimental to her best interests.). Given that it is implausible to suppose that the harm\* of paternalistic intervention always outweighs the benefits of paternalistic intervention, premise 3\* is false.

#### ***9.4.3.3 Rejecting the Incoherence Argument***

I have presented the incoherence argument as follows:

1. P's hard paternalistic interference with Q is justified iff it protects or promotes Q's best interests
- 2\*. P's hard paternalistic interference with Q causes harm\* to Q

3\*. The harm\* caused by P's paternalistic interference with Q outweighs any benefits gained by Q

4\*. (Given 3\*) P's hard paternalistic interference with Q fails to protect Q's best interests

5. (Given 1. and 4\*.) P's hard paternalistic interference with Q is unjustified.

I have shown that given the reinterpretation of premise 2 into premise 2\*, premise 3\* cannot be sustained. For this reason, premise 4\* does not follow, since not all paternalistic interferences will fail to protect Q's best interests because the harm\* of paternalistic interference does not outweigh its benefits. The nature of paternalistic interference thus does not undermine its justification and the notion of justified hard paternalism is not incoherent. BIA can thus withstand the incoherence argument.

### ***9.3 CONCLUDING REMARKS***

In the final chapter of my thesis I have developed an account of justified hard paternalism. My best interests account (BIA) of justified hard paternalism claims that hard paternalistic interferences are justified on the basis that the individual's refusal to consent is not in her best interests (section 9.1) so that hard paternalistic interference is justified iff:

**(1)** P aims to bring it about that with respect to some state(s) of affairs which concerns Q's best interests, Q's choice or opportunity to choose is denied or diminished;

**(2)** P's belief that this behaviour promotes Q's best interests is the main reason for P's behaviour;

**(3\*\*)** P discounts the absence of Q's informed consent or the absence of Q's possible consent if she were to be relevantly informed of P's interference with her choices on the condition that:

**b)** Q's choice is detrimental to her best interests.

I defended BIA against a number of objections that are commonly raised against defences of hard paternalism. After illustrating that hard paternalism is often presumed to be unjustified (section 9.2) I provided an account of what unjustified hard paternalism would entail in light of BIA (section 9.2.1) in which I claimed that hard paternalistic interferences are unjustified if Q's choice is not detrimental to her best interests (section 9.2.1).

Subsequently I presented objections to hard paternalism in the form of the unlikelihood argument (section 9.2.2) and the incoherence argument (section 9.2.5). The epistemic unlikelihood argument (section 9.2.3) was objected to on the grounds that it is plausible to suppose that within a medical context, P is equally or better placed than Q to know which medical treatment will protect Q's best interests. The slippery slope unlikelihood argument (section 9.2.4) was rejected on the grounds that cases of unjustified hard paternalistic interferences, or non-paternalistic interferences with patient free choices could be protected through governance mechanisms and codes of practice. Finally, the incoherence objection (section 9.2.5) was rejected on the basis that it is reliant on a conception of harm\* (see section 5.1) and that given my objective account of best

interests (7.5) the harm\* caused by a paternalistic interference does not always outweigh the benefits of hard paternalistic interventions.

Absent any further objections I have provided an account of justified hard paternalism. Moreover, were this account to be applied in medical practice it would justify the reversal of the prioritisation of the doctrine of informed consent over the duty of care since (given my rejection of informed consent in previous chapters) I have shown that patient well-being can be better protected through paternalistic interference when it is suspected that the patient's exercised free choice to refuse medical treatment is not in her best interests.

## CONCLUSION

The motivation for this thesis was to provide an alternative resolution to the conflict between respect for patient free choice and the goal of medicine to protect patient best interests. This was achieved by providing reasons to reject the doctrine of informed consent and by mounting a defence of hard paternalism.

I began in chapter 1 by providing an overview of the development of informed consent procedures within both medical research and therapeutic practice. I outlined the transition from the traditional ethics of medicine to protect patient best interests as preserved in the 'duty of care' to the current form of medical ethics and its emphasis on the need to respect patient free choice. This was achieved by drawing upon historical atrocities and various ethical justifications for the presence of informed consent procedures in medical settings.

Informed consent procedures only apply to patients who are competent to make medical decisions. In chapter 2 I presented an account of issues surrounding the determination of patient competence. I indicated that, with regard to a risk related standard of competence, it is difficult to determine competence in a way that respects patient free choice and thereby the determination of patient competence is in tension with the purpose of informed consent.

In chapters 3, 4 and 5 I provided a detailed analysis of the nature of free choice in order to assess the central justification for informed consent procedures. In chapter 3 I

developed my own analysis of what is involved in exercising free choice, drawing upon concepts of de jure liberty, de facto liberty, freedom of action and the capacity for autonomy.

In chapter 4 I expanded upon the nature of autonomy as a capacity. I argued that neither minimal nor procedural accounts of autonomy as a capacity suffice to explain why free choices should be respected in medical practice, since it is not possible to determine whether or not an individual has autonomy as a capacity, and so whether she is capable of exercising free choice. On the basis of my rejection of these accounts I argued that only a substantive account of autonomy as a capacity can be used to explain why free choices should be respected under the doctrine of informed consent.

On the basis of my accounts of exercisable free choice and the substantive account of autonomy as a capacity, in Chapter 5 I provided an account of absolutism: the position that patient free choices should be respected above and beyond all other ethical considerations. In Chapters 6 and 7 I rejected absolutism. In chapter 6 I provided a thought-experiment based on possible absolutist worlds. I used this device to argue that the intrinsic and instrumental goods that are claimed to be protected by absolutism are poorly protected in possible absolutist worlds. This conclusion is used for rejecting the model of absolutism that is adopted by proponents of the doctrine of informed consent.

Subsequently, in chapter 7, I assessed and rejected the claim that the patient is the best judge of the nature of her best interests. I evaluated accounts of well-being, defining the medical decision that is in the patient's best interests as the one that is most likely to

protect or improve the patient's overall well-being. I rejected the hedonic mental state and desire satisfaction accounts in favour of the objective list account of patient best interests.

In chapters 8 and 9 I presented an alternative account of medical decision making in the form of hard paternalism. The justification for this account is drawn from the conclusions in previous chapters. In chapter 8 I outlined the different forms paternalism can take. I developed my own criteria of hard paternalism and then used this definition to assess and reject four theories of justified hard paternalism. Finally, in chapter 9 I presented my positive theory of justified 'real hard paternalism' and defended it against possible objections making the case for adopting a practice of hard paternalism in clinical settings.

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