

The Ethics of Deception in Caregiving: A Patient-Centered Approach

by

Rosalind Abdool

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## **Abstract**

Deception is a central issue in bioethics. This emerges most clearly when considering ways of assisting individuals who are incapable of making their own decisions. Deception can be defined as purposefully misleading another to think that something one believes to be false is true. Philosophically, it is a crucial question whether deception should be considered morally indefensible or morally defensible in different clinical scenarios. My dissertation is a novel approach to considering deception in caregiving and provides a new method for assessing when deception is either morally defensible or indefensible.

I ultimately argue that deception ought to only be used after considering several key morally relevant factors and that deception is *prima facie* morally indefensible. I argue that in very rare circumstances deception may be the most morally defensible alternative. These situations are often when a patient is significantly declining with no chance of recovery and there are no other plausible alternatives with a higher benefit-harm ratio in light of the morally relevant factors I explore. Other more rare circumstances include if there were significant chance of benefit to the patient, little chance of harm or risk and no other plausible alternative.

I develop an organizational framework and a clinical framework to help guide caregivers through the decision of whether it is morally appropriate to deceive a patient in unique circumstances. The organizational framework is designed to consider organizational limitations and conditions from which health care administrators can formulate policies on this issue. I argue that constraints on deception include: mental capacity, compliance with treatment (when applicable) and risk of significant distrust, and that necessary conditions include: significant chance of recovery, disclosure and controlled environments. I further developed a case-based (patient-centered) clinical framework, Embedded Specified Principlism (ESP). ESP

is a modification of Beauchamp and Childress' Specified Principlism (SP) and it is both practical for the caregiving environment and provides comprehensive moral justification for determining when and when not to use deception.

I consider several other bioethics models, including feminist bioethics and narrative ethics, and argue that these ought to be incorporated into ESP to highlight the importance of reducing stigma towards vulnerable/marginalized populations, fostering greater trust and other relationships between caregivers and patients and understanding the rich narrative of each unique patient. I further explore three major objections to traditional SP including arbitrariness, systematicity and casuistry and argue for two methods to reduce arbitrariness. On the basis of these arguments and the discussions of the morally relevant factors presented in my dissertation, I ultimately argue that deception in caregiving, although most often is morally indefensible, can be morally defensible in rare circumstances depending on the unique specifications of each patient's experience.

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Rosalind Abdool, University of Waterloo

To Inga Gurney, my greatest inspiration

## Table of Contents

<b>Abstract .....</b>	<b>iii</b>
<b>Acknowledgements .....</b>	<b>v</b>
<b>Table of Contents.....</b>	<b>vii</b>
<b>Introduction.....</b>	<b>1</b>
<b>Chapter 1 What is the Conflict?.....</b>	<b>12</b>
Forms of Deception.....	12
Intention.....	15
Consequence.....	17
Cause.....	18
Naturalness (Expectations).....	23
Current Philosophical Landscape of Deception.....	28
Beneficence.....	29
The Autonomy Account.....	33
The Trust Account.....	39
What is the Conflict?.....	53
Conclusions.....	62
<b>Chapter 2 Alternatives to Deception.....</b>	<b>64</b>
Physical Restraints.....	65
Advance Care Planning.....	82
Absolute Truth-telling.....	99
Conclusions.....	108
<b>Chapter 3 Further Factors to Consider for Deception.....</b>	<b>111</b>
Legal and Professional Constraints.....	112
Informed Consent.....	112
Right to Choose / Right to Treatment.....	113
Right to Personal Health Information (PHIPA).....	118
Truth-telling.....	122
Further Ethical Factors in Favour and Against Deception.....	123
Deontological Factors.....	123
Consequentialist Factors.....	135
Virtue Ethics Factors.....	142
Conclusions.....	150

<b>Chapter 4 Weighing and Balancing Factors .....</b>	<b>152</b>
A Process for Specification, Weighing and Balancing .....	153
Organizational Policy .....	153
Clinical Decision-Making – Embedded Specified Principlism (ESP).....	169
Continuous Revisiting the Use of Deception .....	183
Conclusions .....	185
<b>Chapter 5 A Consideration of Methodological Objections.....</b>	<b>187</b>
Chapter Relevance to Thesis Project.....	187
Methodological Objection 1: Arbitrariness in Weighing and Balancing.....	191
Reducing Arbitrariness .....	191
The Publicity Test.....	195
Methodological Objection 2: Systematicity .....	198
Justificatory Power .....	204
Practicality .....	209
Methodological Objection 3: Casuistry.....	212
Modifications to ESP .....	217
Conclusions .....	219
<b>Conclusion .....</b>	<b>220</b>
<b>Bibliography .....</b>	<b>224</b>



## Introduction

Deception is very common in caregiving, both in healthcare institutions and in caregiving in the community. Eleven percent of patients in nursing homes are given medication covertly, and seventeen percent of patients in specialized dementia units have medication hidden in their food and drink. Deceiving patients is poorly documented and caregivers are hesitant to admit to its practice; this opens the door to abuse of vulnerable populations and to serious safety and risk concerns.<sup>1</sup> The prevalence of deception shows the importance of developing a theoretical approach to justify when deception is morally defensible and when it is morally indefensible. This is what I will do.

Deception purposefully misleads another to believe something that one believes to be false; thus, deception is a central issue in bioethics. This emerges most clearly when considering ways of assisting individuals who are incapable of making decisions for themselves. There is also a disconnect between caregivers using deception and their reluctance to admit to its use. Are caregivers' perceptions of using deception misguided or is their reluctance justified and should we not be using deception in caregiving? Over seventy percent of healthcare staff has faced the decision to administer medication covertly, and almost all agree that deception is justified "on some occasions."<sup>2</sup> When is deception morally defensible and when is it morally unjustifiable; what is the justification?

I will defend the notion that deception is morally defensible in very particular kinds of cases where individuals suffer from significant mental impairment. I will also argue that

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1. Øyvind Kirkevold and Knut Engedal, "Concealment of Drugs in Food and Beverages in Nursing Homes: Cross Sectional Study," *BMJ (Clinical Research Ed.)* 330, no. 7481 (2005): 1–4.

2. Anton Valmana and Joan Rutherford, "Suspension of Nurse Who Gave Drug on Consultant's Instructions: Over a Third of Psychiatrists Had Given a Drug Surreptitiously or Lied About a Drug," *BMJ* 315 (1997): 300–314.

deception can often enhance, rather than impair, autonomy and foster greater well-being, which can override the value of honesty. My dissertation project aims to determine when we ought to honour one value (or multiple values) more than others when they are in conflict for deception in caregiving. Several values involved in the use of deception include beneficence, honesty, trust, respect for autonomy and non-maleficence. Additionally, I will argue that deception can be a more humane alternative than other methods of treatment. I will provide an extensive argument for why one ought to not feel moral guilt for using deception in promoting well-being and preventing unnecessary distress in specific situations related to care-giving. I will also argue that trust can be developed in multiple ways, not only through truth-telling but also through reliability. In developing a theoretical defense of deception in caregiving, it is my aim that my dissertation project can provide caregivers with guidelines for when to use deception, and justification as to why it is morally defensible in those specific circumstances. I will argue for general guidelines that healthcare organizations can adopt, as well as more specific guidance for challenging bioethics deception cases at the bedside.

The kind of deception I discuss is deception related to the treatment and care of patients and not deception used in research. I discuss two main forms of deception. Deception can be used when administering medication, such as hiding medication in food or drink. This form of deception is called covert medication. Covert medication is deceptive because a patient believes that she is consuming a beverage or food without any additional substance, and it is presented as such by the caregiver. However, the caregiver knows that the beverage or food contains more than what is reasonably expected by the patient.<sup>3</sup> I will also discuss deception as

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3. Covert medication is not merely an act of not getting consent directly from the patient, but also involves an act of misleading another without their knowledge and presenting the beverage/food as if it were a regular beverage or food item. An act for which consent is not obtained and no deception is occurring may occur if a patient is being physically restrained, for example.

initiating and/or perpetuating false ideas to relieve suffering. Consider an elderly woman who suffers from dementia who was recently admitted to a nursing home; she lacks mental capacity and wishes to return home to an environment that is unsafe given her medical condition; is it acceptable to inform her that she will only be in the nursing home for a few days, although her stay is permanent, considering that informing her that she cannot return home will cause her much distress? Although these two cases are perhaps most common when considering deception, there may also be cases where deception is morally defensible in other patient populations, for example those populations who lack treatment decisional capacity after sustaining brain injury or even the deception of young children who lack mental capacity. In Chapter One, I will provide further distinctions for different types of deception within the two types of deception that I focus on for my thesis.

I will now further discuss the background of deception in caregiving. Family members and other caregivers who wish to make the person under their care better often use deception out of compassion and sometimes frustration. They can also use covert medication to ensure that medication is taken.<sup>4</sup> I will use the term *caregiver* in a broad sense to include not only healthcare providers who look after patients/clients/residents, but also family members and others who help to look after someone in need of support. Likewise, my use of the term patient extends beyond a typical patient accessing healthcare services (including residents and clients), but also someone who is being looked after by another. For example, this can include a family member with dementia who is being cared for by a spouse in the community. I chose to keep these groups broad because I believe that both of these groups struggle with similar ethical

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4. Scott Stroup, Marvin Swartz, and Paul Appelbaum, "Concealed Medicines for People with Schizophrenia: A U.S. Perspective," *Schizophrenia Bulletin* 28, no. 3 (2002): 537–542.

issues in these cases, and that my thesis would be a useful exploration for both regarding a practical and morally defensible decision-making framework.

Additionally, deception is common not only for providing medication, but also in preventing harms to the patients and to others. For example, consider a seventy-year-old woman who suffers from advanced dementia. She still has possession over the car that she has owned for twenty years. She does not remember that her driver's license has been revoked due to her inability to follow the driving rules as a result of her illness. When she is reminded that she can no longer drive, she becomes extremely distressed being reminded of her loss of autonomy and the difficulties relating to her illness. Her family resorts to deception, telling her that the car needs to be fixed due to a mechanical problem. They feel guilty about deceiving their mother, yet they wish to avoid causing her further distress and harm, and causing harm to others in the community if their mother were to drive.

In framing the discussion of deception in caregiving, currently in Ontario there is no legislative guidance specific to this issue. What is clear is that if a patient has mental capacity to make decisions for herself, consent is required in order to administer any form of treatment. What is mental capacity? I will refer to this concept as both *mental capacity* and *capacity*. Under the Health Care Consent Act 1996 of Ontario, mental capacity is defined as the following:

A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.<sup>5</sup>

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5. *Health Care Consent Act, 1996, 2010, C. 1, Sched. 9.*, 1996, [http://www.e-laws.gov.on.ca/html/statutes/english/elaws\\_statutes\\_96h02\\_e.htm#BK12](http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm#BK12).

Mental capacity means that a person can both *understand* (e.g. acknowledge the basic facts that apply to the decision) and *appreciate* (e.g. recognize how various options will apply to one's personal situation) relevant facts associated with the health care decision. Someone might understand the facts associated with a decision, but not appreciate how it applies to his/her situation. For example, an individual who suffers from an eating disorder may be able to rigorously explain facts about nutrition and how it impacts health in general, but might not be able to appreciate how these facts impact his own body and health.

The facts required for an informed consent are outlined in the Health Care Consent Act 1996 and include, but are not limited to, the nature of the treatment, the benefits, the risks, any alternatives and the consequences of not proceeding with any treatment.<sup>6</sup> Capacity is also treatment and time specific. It can be regained after a loss, often due to treating delirium and/or psychosis, for example.

Consent is required from a legally appointed substitute decision-maker (SDM), when a patient no longer has capacity.<sup>7</sup> No further guidance is provided as to when it is legally or morally defensible or indefensible to deceive a patient. In Chapter Four, I will discuss in further detail the professional (college, association, etc.) duties that often conflict when considering deception, as well as general legal concepts that help to inform this issue.

Comparatively, other provinces than Ontario lack definitive guidance around the use of deception in healthcare. Most frequently, if there are policies or guidelines, they have been developed for covert medication specifically and provide a brief statement on the issue. One such example is a document produced by the College of Registered Nurses of Manitoba. The

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6. *Health Care Consent Act, SO 1996, C. 2, Sched. A; 2010, C. 1, Sched. 9, 1996*, [http://www.e-laws.gov.on.ca/html/statutes/english/elaws\\_statutes\\_96h02\\_e.htm](http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm).

7. Kirkevold and Engedal, "Concealment of Drugs in Food and Beverages in Nursing Homes," 1–4.

document does not provide clear guidance on how to make a decision, yet highly cautions their nurses to refrain from covert medication given several professional duties.<sup>8</sup> Similarly the College of Registered Psychiatric Nurses of B.C. does not support the use of covert medication.<sup>9</sup>

Many groups in the United Kingdom, however, have created guidelines and documents on covert medication. For example, the National Institute for Health and Care Excellence, Northamptonshire Healthcare (NHS Foundation Trust) and the Royal College of Psychiatrists all have position statements on this issue.<sup>10</sup> These organizations are much more open to deception being morally defensible in certain circumstances, and provide various steps and questions to guide professionals through these decisions.

Healthcare providers can use deception to ensure that patients are taking their medication for recovery. It is estimated that twenty to fifty percent of psychiatric patients are non-adherent with taking medication. This estimate rises to seventy to eighty percent for patients suffering from schizophrenia.<sup>11</sup> Taking medication for patients suffering from psychotic illnesses can often reduce symptoms of the illness, and allow patients to regain mental capacity. I will argue that patients can regain substantial autonomy to make decisions for themselves, significantly increasing their well-being.

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8. College of Registered Nurses of Manitoba, “Covert Medication Administration,” July 2006.

9. College of Registered Psychiatric Nurses of British Columbia, “Dose Form Modification of Medication: Evidence Based Guidelines,” September 2011.

10. National Institute for Health and Care Excellence, “Managing Medicines in Care Homes,” March 2014; Northamptonshire Healthcare (NHS Foundation Trust), “Covert Administration of Medicines Policy and Guidelines,” July 2013; Royal College of Psychiatrists, “College Statement on Covert Administration of Medicines,” *The Psychiatrist: Formerly the Psychiatric Bulletin* 28 (n.d.): 385–386, accessed January 10, 2015.

11. Robert Breen and Joshua T. Thornhill, “Noncompliance with Medication for Psychiatric Disorders: Reasons and Remedies,” *CNS Drugs* 9, no. 6 (1998): 457–471.

Richard Griffith highlights resource allocation concerns with medication non-compliance: “This failure to comply leads to drug wastage, mismanagement of medical conditions and readmission to hospital, as well as adverse reactions for the patient. For healthcare managers, non-compliance results in an extraordinary waste of resources, running to billions of pounds.”<sup>12</sup> Not only can compliance benefit the patient, but it also benefits society as a whole.

Deception can occur for what many would consider morally objectionable reasons. Behaviour modification is one reason why covert medication is used, subduing patients to make it easier for *caregivers*. The patient’s interests are subordinated to the caregivers’.<sup>13</sup> For example, if a patient is particularly hostile or agitated, staff may recommend psychotropic medications be prescribed by the physician, often via phone without a physician’s physical presence. Patients with severe cognitive impairments, aggressive behaviour and reduced abilities to perform daily activities are more subject to covert medication than other patients.<sup>14</sup> A major concern is that staff assessment (as opposed to physician assessment) trumps actual psychiatric diagnosis.<sup>15</sup> According to a study conducted by Sørensen et al., sometimes physicians do not even see patients, but rather rely on staff perceptions of the psychiatric illness when prescribing medications.<sup>16</sup> Sedation of patients is also used more often than

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12. Richard Griffith, “Managing Medical Compliance,” *British Journal of Healthcare Management* 16, no. 8 (2010): 402.

13. Lisbeth Sørensen et al., “Determinants for the Use of Psychotropics among Nursing Home Residents,” *International Journal of Geriatric Psychiatry* 16, no. 2 (February 2001): 147–152.

14. Kirkevold and Engedal, “Concealment of Drugs in Food and Beverages in Nursing Homes,” 1–4.

15. Sørensen et al., “Determinants for the Use of Psychotropics among Nursing Home Residents,” 152–153.

16. *Ibid.*, 147–154.

needed.<sup>17</sup> This creates concern that patients may be given covert medication for morally unacceptable reasons, solely to alleviate staff concerns, rather than acting in the patient's best interests and considering other less invasive alternatives. The result can be that patients are quite sedated and unable to participate in other activities that bring them much benefit and quality of life, before other behaviour modification methods are explored.

The decision to use covert medication is often arbitrary. There is no formal decision procedure for deciding to use covert medication, which is morally alarming.<sup>18</sup> On what basis are these decisions made? Whose interests are considered? Are we respecting the patient's wishes and values? Without guidelines and justification, there is room for abuse of power and poor decision-making. Although there are concerns with abuse of power by advocating for deception (under strict limitations) in caregiving, there may be *more* abuse of power if these practices continue unregulated. This is one reason why it is important to provide justification for when it is morally appropriate to use deception. My dissertation is not aimed at being a harm-reduction model, even though the outcome of my dissertation will hopefully lead to a reduction in current cases where deception is being used and is morally indefensible. I will argue that deception not only reduces these kinds of morally unjustified cases, but deception can be morally defensible for caregivers in certain other cases.

Furthermore, trust in healthcare and healthcare institutions can be fostered greatly if these practices are brought to the public's attention and justification is made transparent for the use of deception in defensible cases. Transparency and publicity of treatment and other healthcare processes are essential for ensuring accountability. Caregivers will be less likely to

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17. Astrid Sonntag et al., "Does the Context Matter? Utilization of Sedative Drugs in Nursing Homes—a Multilevel Analysis," *Pharmacopsychiatry* 39, no. 4 (July 2006): 142–149.

18. Kirkevold and Engedal, "Concealment of Drugs in Food and Beverages in Nursing Homes," 1–4.



abuse their position if deception is clearly documented and justification is provided for its use. The decision-making framework and guidelines that stem from my theoretical defense also allow caregivers to consider carefully the harms, benefits and alternatives when contemplating the use of deception.

I will use a pluralist approach to explore this problem. I follow in the tradition of pluralists, such as W.D. Ross and others who argue that there are many irreducible goods (or values) that serve as the basis of ethical principles.<sup>19</sup> My thesis will not use a particular normative ethical theory, but rather I will adopt the approach that multiple prima facie values and principles can come into conflict.<sup>20</sup> I use a pluralistic approach because my argument is based on applied ethics, and how we ought to make practical decisions in cases. I further choose this approach because other common ethical theories do not take into consideration all morally relevant reasons – a pluralistic approach does. For example, consequentialist arguments only consider the consequences of actions and often do not allow for reasons such as the intrinsic value of autonomy. Deontology would not consider violating autonomy for any reason, whereas I argue there are other values that might do so. I will however, consider many different reasons that may be considered traditionally deontological or consequentialist as part of the pluralist reasons that ought to be taken into account when determining what one ought to do.<sup>21</sup> In moral conflict, these values and principles ought to be weighed and balanced to determine which of these values and principles override others in certain circumstances. I will

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19. For example, see Judith J. Thomson, “The Right and the Good,” *Journal of Philosophy* 94, no. 6 (1997): 273–298; Brad Hooker, “Ross-Style Pluralism versus Rule-Consequentialism,” *Mind* 105, no. 420 (October 1996): 531–553.

20. For example, see William David Ross, *The Right and the Good* (Oxford University Press, 2002).

21. Arguments against each of the canonical ethical theories are beyond the scope of this paper, so I intend to use a more widely accepted account of principlism.

explore all of the reasons, constituted by values and principles, involved in deception in caregiving and I will explain why we ought to balance and weigh them in a non-arbitrary, patient-centered way.

My theoretical approach is greatly informed by Beauchamp and Childress' methodology. This methodology uses balancing and weighing factors for and against deception, based on biomedical ethics principles and values.<sup>22</sup> Principlism offers a starting point of bioethics values, while specification narrows the scope dependent on the case. Beauchamp and Childress remark: "prima facie principles do not contain sufficient content to address the nuances of moral problems."<sup>23</sup> Specification adds content to the principles. The weights of the values within the scope of the case help to determine which value(s) ought to be honoured. Balancing does not create distinct guidelines for like cases, but allows for the complexity of each case to be considered. In weighing and balancing factors for and against deception, I will use reflective equilibrium.<sup>24</sup> Reflective equilibrium involves examining the principles of biomedical ethics in light of the specific convictions of each individual. Both the principles and individual convictions are involved in exploring what one ought to do; both or either can be revised in light of the other. I use specified principlism and reflective equilibrium because they are the most widely accepted methodology in biomedical ethics. I further justify using this methodology against two other standard bioethics decision-making procedures, the

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22. Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 6th ed. (New York: Oxford University Press, 2009); Henry S. Richardson, "Specifying, Balancing and Interpreting Bioethical Principles," *Journal of Medicine and Philosophy* 25, no. 3 (2000): 285–307.

23. Beauchamp and Childress, *Principles of Biomedical Ethics*, 17.

24. *Ibid.*, 381–387.

moral system approach of Gert, Culver, and Clouser, and the kind of casuistry defended by Strong.<sup>25</sup>

In the first chapter, I will discuss precisely where the conflict occurs between various principles and values. The second chapter is my argument that alternatives to deception are inadequate in certain situations, and one ought to consider deception as a genuine conflict. I will present moral factors both against and in favour of using deception in the third chapter, through discussing several major ethical theories. In the fourth chapter, I will discuss weighing and balancing the factors presented in the third chapter, using both specified principlism and reflective equilibrium. This chapter will provide justification for when deception is morally defensible, and for when it is morally indefensible. I include an analysis at both the organizational and the clinical levels of decision-making. I will not provide a formal policy for the organizational framework, as creating a document such as this requires extensive input from each various organizational stakeholders (e.g. legal representation, clinical committees, etc.) and is approved and designed specific to each organization. However, the organizational framework provides important content for the basis of a policy. The final chapter is a theoretical defense of the methodology that I am using, in light of other theoretical approaches in bioethics, including the moral system approach and casuistry. Ultimately, my thesis is a theoretical defense of when deception is morally justifiable, and when it is morally indefensible in caregiving. I will determine the morally relevant features of the conflict, and then provide justification for the use of deception in light of these features. I will also defend my account against theoretical objections to the use of deception in caregiving.

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25. Bernard Gert, Charles M. Culver, and K. Danner Clouser, *Bioethics: A Systematic Approach* (Oxford: Oxford University Press, 2006); Carson Strong, "Critiques of Strong and Why They Are Mistaken," *Theoretical Medicine and Bioethics* 20, no. 5 (September 1999): 395–411.

## Chapter 1

### What is the Conflict?

Before directly engaging with current philosophical discussions on the conflict between principles, I will further define deception in light of its various forms. I will discuss several forms of deception under two broad categories – passive and active – and will argue that there is no morally relevant difference between these two forms, and both should be morally examined with the same scrutiny.

### Forms of Deception

There are two broad categories of deceptive acts: active and passive. Active forms of deception involve the deceiver either stating something that she believes is false or explicitly performing an act to deceive. Examples of active deception can include most forms of lying, concealment (e.g. covert medication) and cheating. Passive deception requires that the deceiver omits certain information in order to deceive or bend the truth.<sup>1</sup> Passive deception is often considered as telling “half-truths” and/or dissimulation. Examples of passive deception can include omissions (e.g. leaving out discharge options when discharge planning, placebos and distractions) and bending the truth (e.g. via exaggerations or underestimations). Covert medication does not clearly fit into either category, since it involves both an action (placing the medication into the beverage or food) and an omission (not providing that information to the deceived). I included it in the active category since it is traditionally considered the more morally contentious category, but nonetheless it contains elements of both.

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1. Roderick M. Chisholm and Thomas D. Feehan, “The Intent to Deceive,” *The Journal of Philosophy* 74, no. 3 (March 1, 1977): 143–59.

Other questionable forms of deception include nudging and framing.<sup>2</sup> These two concepts are very similar such that they involve manipulating the way in which information is presented (framing) and the way in which options are presented (nudging), such that the agent wishes the deceived to pick a particular option over others without her knowing that it was crafted for her to do so. These forms can be considered manipulative, but not entirely coercive. Deception falls somewhere between rational persuasion and coercion. Deception is not quite coercion, where someone is fully aware of the act, such as holding someone down and administering medication. It is also not truthfully allowing someone to exercise her full autonomy such as through rational persuasion. Instead, deception allows for some autonomous decision-making, while disallowing other forms.<sup>3</sup>

There are many other philosophical discussions that debate whether active versus passive acts ought to have equivalent or more/less moral worth or blame. Most notably, the active versus passive euthanasia debate engages this dialogue most commonly in health care. For example, there is generally shared feeling that in most healthcare settings, it is moral to allow someone to die of an underlying disease, whereas it is morally blameworthy to administer a dose of morphine that would stop someone's heart under the same circumstances. Even though currently in Ontario it is illegal to participate in active euthanasia, there is a general opinion that this act is worse than passively allowing someone to die.<sup>4</sup> There is difficulty in applying passive euthanasia practically and what actually constitutes passive

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2. For example, see Richard H. Thaler and Cass R. Sunstein, *Nudge: Improving Decisions about Health, Wealth, and Happiness* (New Haven: Yale University Press, 2008).

3. I will discuss this in further detail when I introduce the concerns related to deception and autonomy.

4. See for example: American Medical Association, "AMA Policy on End-of-Life Care," accessed March 6, 2015, <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/about-ethics-group/ethics-resource-center/end-of-life-care/ama-policy-end-of-life-care.page>. The Canadian Medical Association is, however, currently reconsidering its position on this issue.

euthanasia, given that palliative care is considered a withdrawal in many instances of active treatment. This debate in practice is still quite controversial.

James Rachels is the most recognized philosopher who has challenged traditional views that there is a morally relevant distinction between active and passive forms of euthanasia. In Rachels' chapter on "Active and Passive Euthanasia" he persuasively argues that agents ought to be held morally accountable for passive forms of euthanasia, just as one would for active forms. Nonetheless, he argues that sometimes active forms of euthanasia are more humane than passive forms, such as to alleviate inordinate suffering quickly, rather than allowing suffering for sometimes a lengthy dying process.<sup>5</sup> His argument rests on the idea that for both forms of euthanasia, active and passive, the intentions as well as the consequence are ultimately the same: the intention is for the patient to die, and the consequence is a hastened death.<sup>6</sup>

Nonetheless, the *cause* of death in either case is quite different. Should *cause* be a morally relevant difference? Some argue that cause is irrelevant in these cases, as omissions can ultimately contribute to death (e.g. omitting the provision of antibiotics for an infection in order to allow a patient to die).<sup>7</sup> However, the role and purpose of palliative care is often to treat symptoms, rather than to prolong life or provide aggressive treatment, which can be considered another form of omission.

Additionally, some have argued that the difference rests upon what is *natural*. For example, technology and life-sustaining machinery, such as ventilators, prolong the disease

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5. James Rachels, "Active and Passive Euthanasia," in *Bioethics: An Introduction to the History, Methods, and Practice*, 2nd ed. (Jones & Bartlett Learning, 2007), 64–69.

6. *Ibid.*, 67.

7. Eve Garrard and Stephen Wilkinson, "Passive Euthanasia," *Journal of Medical Ethics* 31, no. 2 (February 2005): 66.

process and maintain someone's life, as opposed to allowing someone to die. The difference between active and passive euthanasia is that passive euthanasia allows *nature to take its course*, whereas active euthanasia involves unnaturally administering lethal medications, for example.<sup>8</sup> Ought the *nature distinction* be a morally relevant difference between active and passive euthanasia? Hopkins argues against this notion on grounds that describing passive euthanasia as natural simply provides us comfort, as opposed to feeling guilt for contributing to the cause or hastening of death.<sup>9</sup> Hopkins further argues that people are mistaken to believe that *naturalness* does not involve intervention and that it is a neutral stance.<sup>10</sup> Rather, passivity is an intervention, which often requires a withdrawal of life-sustaining treatment. Hopkins concludes that letting die and killing are not morally different.

Let us now return to the active versus passive deception debate to determine whether this argument by analogy applies to forms of deception. I have discussed four key factors in the active versus passive euthanasia debate: intention, consequence, cause and naturalness. I will explore each individually as it applies to deception in healthcare.

### *Intention*

In this section, I will list and discuss three broad kinds of intentions for deceiving. Aquinas reflects on three distinct types of lies – malicious, jocose and officious. Malicious lies intend to do some kind of evil. Jocose lies are told in jest or as a joke. Officious lies are what we

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8. Patrick D. Hopkins, "Why Does Removing Machines Count as 'Passive' Euthanasia?," *The Hastings Center Report* 27, no. 3 (May 1, 1997): 29–37.

9. *Ibid.*, 30.

10. *Ibid.*, 31.

consider “white lies” – lies, which are intended to be helpful.<sup>11</sup> Despite forming these three categories for various types of lies, Aquinas maintains that they are all morally impermissible acts. Aquinas considers any kind of deception, intentionally misleading others, to be inherently wrong, despite intentions and/or consequences.<sup>12</sup> I focus on officious lies in this section, as they are most applicable to the use of deception in caregiving. Hence, I will explore officious intentions to argue that there is no morally relevant difference in cases of active and passive deception.

Before Thomas Aquinas’ views on deception and, more specifically, on lying, St. Augustine held very rigid views on lying. Augustine held an absolutist position against any form of lying.<sup>13</sup> What is also interesting is that both Augustine and Aquinas argue that the choice to withhold information (passive deception) is not considered morally indefensible, despite this kind of act having both the intention and the consequence of deception.<sup>14</sup>

Nonetheless, I believe that the three types of lies (malicious, jocose and officious) can be useful when considering the prima facie rule or principle to not deceive and the circumstances under which it may be permissible to lie and/or to deceive. First, I believe that malicious lies, those which intend only to do harm, are morally impermissible and this is relatively uncontroversial.

Jocose lies are intended to be in jest or for humorous reasons. This category of deception is beyond the scope of this paper, as it does not directly relate to caregiving

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11. Joseph Boyle, “The Absolute Prohibition of Lying and the Origins of the Casuistry of Mental Reservation: Augustinian Arguments and Thomistic Developments,” *American Journal of Jurisprudence* 44, no. 1 (1999): 54.

12. *Ibid.*, 61.

13. *Ibid.*, 44–66.

14. *Ibid.*, 63.



deception. However, one might imagine that there would be limitations on the kinds of acts of deception that are morally permissible even within the jocose category – for example, some *pranks* that involve deception may not be considered funny to the deceived, and may ultimately cause significant unwanted harm to the deceived and/or to others.

Lastly, let us consider the most applicable form of lie to my thesis – the officious lie. Officious lies have the intention to do good for others. This is a paternalistic approach to doing good for others – given that the deceiver believes she knows what is best for the deceived. The intention in these kinds of cases is arguably selfless and the aim is only towards benefitting the deceived and perhaps others affected by the decision.

Let us explore officious intentions across both passive and active forms of deception. For both active and passive deception, a morally acceptable intention would be of the officious kind – to do good for the patient. Doing good for the patient includes considering what the patient would want and the kind of quality of life acceptable to the patient during moments of lucidity.<sup>15</sup> This condition is necessary, but insufficient when considering the moral permissibility to deceive. I will discuss additional criteria that ought to be fulfilled in prospective sections in this chapter, as well as the process of weighing and balancing this intention with other bioethics principles – such as the duty to do no harm, whether or not this is the intention of the deceiver. Hence, there is no morally relevant difference of intention between passive and active forms of deception.

### *Consequence*

Related to intention is consequence, especially the desired consequence of deception. It is difficult to determine what the actual consequences or outcomes will likely be of deception. In

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15. I will discuss this further in the decision-making framework section of this chapter.

Chapter Three I will discuss that there are a plenitude of different factors that one ought to consider when reflecting on potential outcomes, however, the actual events that transpire may be different from those which were expected.

It is necessary to consider the potential negative consequences associated with deception. For example, is interaction with other medications or pharmaceuticals likely? If the patient discovers that she was deceived, how will this impact the invaluable trust-relations with the caregiver and healthcare system more broadly? I will return to this important component later when outlining the decision-making procedure in Chapter Four.

On the other hand, let us consider the potential positive outcomes. If a patient successfully takes her medication and regains decision-making capacity, the caregivers may be able to negotiate a treatment plan with her and fully comprehend her autonomous wishes. Again, a detailed analysis of potential consequences will be discussed in Chapter Three and a decision process presented in Chapter Four.

Other considerations regarding consequences include the likelihood that the medication will be successful or helpful given the patient's condition. In cases where patients will not regain autonomous capacities, such as for Alzheimer's disease, and deception is used to calm or relieve stress for the patient, one must consider the effectiveness of deception. In either passive or active forms of deception, the concerns related to consequences will be the same. Hence, consequences do not provide a morally relevant difference.

### *Cause*

Questions of causation have traditionally been and continue to be very complex and contentious in philosophy – I will not provide significant detail regarding causation. A more accurate term might be *involvement* and the degree to which active and passive forms influence

the deceived to believe a false belief. Active forms of deception more clearly demonstrate greater involvement in the act of deception. For example, lying, the assertion of a statement that the deceiver believes to be false as if it were true, is more likely to close the gap such that the deceived will believe the false statement.

Passive forms of deception often require less involvement such that the deceived will believe something false. For example, these forms involve omitting certain facts to sway the deceived to believe something that the deceiver believes is false. The person who is deceived makes the final conclusion or leap. One might argue that even in cases of active deception the deceived makes the final inference. This may be true, but passive deception does not explicitly state or show that inference or conclusion, whereas active deception does. The deceiver has knowledge that the deceived does not, and she frames and composes the conversation or scenario in such a way that the deceived will *most likely* believe what the deceiver believes to be false, but one can argue that more of the gap is filled and ultimately owned by the person who is deceived. Drawing the conclusion that the false belief is true is a matter of degree between passive and active deception, with active deception moving the deceived closer to that conclusion.

As an analogy, let us discuss Rachels' well-known example of the two men, Smith and Jones, who each gain a significant inheritance if their respective cousins die. Smith enters the bathroom and drowns his cousin, actively participating in the cousin's death. Jones has the full intention to drown his cousin, but enters the bathroom as his cousin is in the midst of already drowning; Jones decides to watch to make sure that his cousin dies, but does not participate in

this act.<sup>16</sup> Rachels challenges his readers to find a morally relevant difference between the two scenarios and argues that both Jones and Smith ought to be held equally morally responsible.

Just as Peter Singer describes that the deaths of many impoverished children and adults across the world are preventable, Rachel argues that in both the Smith and Jones cases, the cousins' deaths were also preventable.<sup>17</sup> Not actively contributing to the act, but rather passively allowing it to occur when an agent can do something (and at little cost to the agent, according to Singer), is equally morally blameworthy according to Rachels and Singer in either case. There is no moral difference between active and passive acts.

I argue along the same lines for both active and passive deception. Despite the active form involving a more direct impact, the passive form also impacts the deceived in such a way that could have been prevented by the agent and at little cost to the deceiver. Hence, regarding cause – both active and passive deception influence cause the deceived to believe something that the deceiver believes to be false, and the degree of involvement is not a moral difference.<sup>18</sup>

One might argue that being more explicitly involved in the deceit is different from just *allowing someone to believe something false*. Let us explore this distinction. Explicit deceit is the active form described above. Passive deceit involves omitting or bending the truth as well as, arguably, nudging and framing. Both active and passive forms of deceit mentioned above involve the agent *doing something*, whether that be making an assertion or arranging options in a particular manner with the aim of manipulating belief. Another sub-category within passive deceit involves allowing someone to continue to believe something that is not true, despite the

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16. Rachels, "Active and Passive Euthanasia," 64–69.

17. Peter Singer, *The Life You Can Save: Acting Now to End World Poverty* (Random House, 2009).

18. There is still on-going disagreement regarding differences between active and passive euthanasia – Daniel Callahan, for example, argues that the cause of death between active and passive euthanasia is quite different; the former being the agent administering a chemical and the latter being the disease itself.

observer/listener believing that it is not true. Consider for example, an elderly patient in a long-term care facility with advanced Alzheimer's disease. He keeps telling the staff that his wife will be coming to visit him in a couple days time and that he is looking forward to her visit, even though she passed away a number of years ago. Staff does not correct him about her death and allows him to continue to hold this belief.

There are different reasons why one could choose to not disclose additional information. For example, it could be unsafe to disclose, it may not make a difference in the other person's belief if one disclosed the information, or one could genuinely wish to deceive by not providing the additional information. Does it matter whether the deceiver is the actual *conduit* for the misguided information? Is there a morally relevant difference for cases when the deceiver is or is not the conduit? Is this situation (where no information is actually transferred to another person) actually an act of deception?

Let us explore the definition of deception again. Deception involves purposefully misleading someone to believe something that one believes to be false. Chisholm and Feehan argue that causing someone to cease to have a true belief and preventing someone from acquiring a true belief are included as forms of deception.<sup>19</sup> They list these kinds of deception under acts of omission.<sup>20</sup> Mahon summarizes the Chisholm and Feehan definition of lying in the following paragraph:

To contribute causally toward another person's acquiring a false belief, or continuing to have a false belief, or ceasing to have a true belief, or being prevented from acquiring a true belief, or to allow another person to acquire a

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19. Chisholm and Feehan, "The Intent to Deceive."

20. Mahon argues that these kinds of acts should not be considered deception, but rather are merely keeping someone ignorant. However, by withholding information to someone when it could change their false belief, this seems like an act of deception via omission. See James Mahon, "A Definition of Deceiving," *International Journal of Applied Philosophy* 21, no. 2 (2007): 181–186.

false belief, or to continue to have a false belief, or to cease to have a true belief, or to continue without a true belief.<sup>21</sup>

The first condition, summarized in the quotation above, involves the purpose or intention of the deceiver for the deceived to have the false belief. The second condition, which I contribute to this discussion, is that in order for an act to rightly be considered as deceptive, there must be a reasonable expectation that the deceived would generally want to know the information that the deceiver believes is true (that is being withheld, transformed or lied about) or find the information important and/or useful. I will return to this additional condition when discussing the value of trust and the role of expectations in caregiving. It is important to note, however, that in the healthcare context there is a stronger obligation to provide the truth and the expectation that relevant information will be provided is stronger than in regular contexts. The kind of relationship will influence the obligation to tell the truth.<sup>22</sup> I do not argue that it is an absolute principle, but at least the strength is affected by the relationship between the two agents. I believe that this definition includes the cases where the deceiver refuses to provide truthful information, without being an explicit *conduit* of that information. Hence, omissions can equally be considered deceptive. Whether the deceiver is a direct or indirect conduit of deception is not a morally relevant difference in cases of deception.

With this additional condition, both active and passive acts can be considered deceptive and our deceiver or agent can be held morally blameworthy or praiseworthy, depending on the situation, for either act. Let us examine the fourth and final morally relevant difference: naturalness.

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21. Ibid., 186.

22. Another example to consider is one of two friends, and one friend is aware of information that the other would want to know or would find important. The principle to tell the truth will be dependent on weighing and balancing competing principles. For example, could significant harm come from disclosing this information? The nature of the relationship is such that the friend should transmit the information to the other friend.

### *Naturalness (Expectations)*

The discussion of naturalness is significantly different between the active/passive euthanasia debate and deception. Deception does not involve a *natural* process as with allowing someone to die of terminal illness, but rather involves an interaction between two (or more) individuals with the deceiver acting intentionally to deceive. One way in which to consider naturalness relates to the previous discussion of intention and expectations. Deception is founded upon interactions among persons – what information would a recipient reasonably expect to be communicated in an interaction with another? Instead of natural, the term *expectations* will be used to describe this relationship.

Considering what is expected from one individual to another is very complex and can be somewhat subjective. What grounds expectations? Where do they come from? If the deceiver and the deceived disagree on the expectation of what one would reasonably want to know, whose expectation should we rely on for moral judgment given the deceiver-deceived relationship?

The OED defines expectation as follows: “A strong belief that something will happen or be the case.”<sup>23</sup> Expectations involve making predictions about others’ (and perhaps one’s own) behaviours. Castelfranchi argues that expectations must involve something beyond mere prediction or what is likely to come to be – they include a motivational or active component, a *concern*.<sup>24</sup> The concern relates to a goal or what the person would want or desire to happen. In cases of deception, the deceiver intentionally chooses to not disclose information that she

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23. “Expectation,” *Oxford Dictionaries* (Oxford University Press, 2015), <http://www.oxforddictionaries.com/definition/english/expectation>.

24. Cristiano Castelfranchi, “Mind as an Anticipatory Device: For a Theory of Expectations,” in *Brain, Vision, and Artificial Intelligence*, ed. Massimo De Gregorio et al., Lecture Notes in Computer Science 3704 (Springer Berlin Heidelberg, 2005), 263.

believes the deceived would have wanted to know under normal circumstances. For example, if Kathy were hiding medication in Tarek's food, under regular circumstances or norms of society, Tarek would want to know that he is receiving the medication. Additionally, if Omar wanted to see his partner and she had passed away, one would reasonably think to tell Omar about his partner's death. This is one reason why deception is not intuitive as a plausible treatment conduit, because under regular circumstances or under *usual* social norms, one would disclose this kind of information, unless one had good reason to not disclose (e.g. it was disproportionately harmful to disclose) or someone was being malicious. We value autonomy and the ability for people to make decisions for themselves. Hence, one would reasonably expect that this information would be provided.

What matters in the cases that I am discussing – the expectations of society more generally or the expectation of the person him- or her-self? On the one hand, if the former is what matters, then we ought to consider what reasonable people in society would expect regarding the transmission of information one believes to be true. Practices within an organization influence expectations among others in society – for example, if people think that their medication will be hidden in their food, this may cause fear and prevent people from seeking help when ill in future, especially those who already have significant clinical anxiety and paranoia. On the other hand, if the latter is what we ought to consider, we need to implement a patient-focused approach and think about what each individual would want to be disclosed, when she is or was capable of making the decision. Each person brings a unique foundation upon which expectations are formed. Although person-focused and patient-centered care aims to arrange treatment such that it is specific to each unique patient's needs, actions within the healthcare system need to have limitations based on legal, professional and ethical



reasons and duties. The question posed in my thesis is whether deception can reasonably fall within the scope of ethical practice in the current healthcare system.

In the discussion of naturalness, it is important to understand patient-centeredness through the lens of expectations to capture what is anticipated and required in an exchange. To reflect further, I will consider questions such as where do expectations come from and when is it reasonable to fulfill them? Expectations stem from many various sources. As Castelfranchi describes, expectations are essentially about goals.<sup>25</sup> They are grounded in a stake or a concern that we have for the way that things are likely to and should transpire. I would also assert that expectations are value-laden. They are grounded in the values that we have, based on our experiences and what matters to us.

In the healthcare setting, there are often expectations regarding the following: treatment options available, one's role as caregiver, one's role as SDM, the role of healthcare team, discharge options and continued services, the probability of hope and recovery and, of course, expectations surrounding length of time for recovery, length of stay in the organization, to name just a few. Each of these notions can be tied back to a value. For example, the role of the caregiver is often linked heavily to the value of promoting health and well-being along with the duty to look after those with whom one has a relationship.

Expectations and attitudes are formed from many different sources.<sup>26</sup> Some sources include religion, family, friends, culture, society, education, personal development etc.. Other sources can include past experiences in healthcare, (one's self, family member, neighbour, friend), the media (news, television, movies, YouTube), Dr. Google, stories from other people

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25. Ibid., 258–276.

26. Eva-Marie Kessler, Sabrina Agines, and Catherine E. Bowen, "Attitudes Towards Seeking Mental Health Services among Older Adults: Personal and Contextual Correlates," *Aging and Mental Health* 19, no. 2 (February 1, 2015): 182–91.

the patient and/or family knows and discussions with various health care team members. Expectations can be conscious, subconscious, intentional, or non-intentional. For example, a person may not be aware of the influences from her culture that have contributed to the expectations that she has of her interactions with the healthcare system. As a different example, someone may be able to articulate and personally own the specific expectations that she has, given her understanding of her religion.

If we consider the patient-focused approach, we should explore the expectations of each unique patient to determine their beliefs and concerns related to healthcare – what do they believe will happen in healthcare and what do they wish to happen?<sup>27</sup> Patient-centered care involves attending to these expectations, within realistic limitations. Jennings et al. state: “By attending to patients’ needs, values, and preferences, satisfaction can be enhanced, thus boosting service quality.”<sup>28</sup> However, there ought to be reasonable limitations set on what the healthcare provider and other caregivers can and cannot do.

Ultimately, I believe that healthcare providers should first consider some broad limitations on the use of deception. Subsequently, if the use of deception is acceptable at the broadest level, the decision to use deception should be focused on each unique patient’s experience, clinical indications and expectations of the healthcare system to determine whether deception is acceptable or not. In Chapter Four I will outline specifically the organizational and clinical limitations and conditions.

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27. Glyn Elwyn et al., “Shared Decision Making and the Concept of Equipoise: The Competences of Involving Patients in Healthcare Choices,” *The British Journal of General Practice* 50, no. 460 (November 2000): 892–99.

28. Bonnie Mowinski Jennings et al., “What Really Matters to Healthcare Consumers,” *Journal of Nursing Administration* 35, no. 4 (2005): 173.

To summarize the naturalness comparison, both active and passive forms of deception involve expectations regarding what information should be provided to another person, especially in the context of healthcare and what information a patient would want and/or expect to know about her treatment and/or her circumstances. Regardless of whether information is directly transferred or if it is passively omitted, there are expectations surrounding the transmission and delivery of this information. This is precisely why we have developed strict guidelines and legislature around informed consent more broadly and consent practices in research.

In summary, I discussed different forms of deception in detail, including both active and passive forms. In order to assess the morally relevant differences between active and passive forms, I used an argument by analogy with debates surrounding active versus passive euthanasia in healthcare to consider four possible morally relevant factors including: intention, consequence, cause and naturalness. I argued that there is no morally relevant difference between active and passive forms of deception in caregiving. I further contributed to this discussion by adding the following: in order for an act to be considered deceptive, there must be a reasonable expectation on behalf of the deceiver that the deceived would want to know the truthful information or find the information important and/or useful. This additional condition helps to explain why passive omissions can still be intentionally harmful to the deceived despite the deceiver seemingly playing a minimal role in the act. In this section I further discussed the importance of exploring expectations and how they shape what is considered to be deceptive. In moving forward, I have argued that both passive and active forms of deception ought to be considered equally morally praiseworthy/blameworthy depending on the specific circumstances. I will now shift gears and discuss the current philosophical landscape of

deception in caregiving and why I believe that the way the conflict is currently framed should be expanded.

### **Current Philosophical Landscape of Deception**

The conflict that arises from the use of deception in bioethics is often argued as being between either respect for autonomy and beneficence or trust and beneficence. I will refer to the first way of interpreting the conflict between respect for autonomy and beneficence, as the Autonomy Account. The second explanation of the conflict, between trust and beneficence will be referred to as the Trust Account. There are few other articles that discuss the conflict as being more complex, but the general landscape revolves around these two accounts, which is why I will address them accordingly.<sup>29</sup>

I will argue that these accounts are deficient especially in cases of patients who lack mental capacity.<sup>30</sup> The real conflict occurs between a plurality of values. These values include but are not exclusive to honesty, beneficence, trust, non-maleficence, justice and respect for autonomy. Caregivers are torn between multiple values; when caregivers use deception they often feel as if they have acted morally blameworthy for doing so, but if they do not deceive their patients they also feel morally blameworthy for not being able to provide care and to relieve suffering. There is no easy answer to this conflict. Various values and principles pull the caregiver in different directions. What ought the caregiver do? In this chapter, I will show

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29. See for example: Erick K. Hung, Renée L. Binder, and Dale E. McNiel, “Covert Medication in Psychiatric Emergencies: Is It Ever Ethically Permissible?,” *Journal of the American Academy of Psychiatry and the Law* 40, no. 2 (2012): 239–245.

30. Laurence B. McCullough, John H. Coverdale, and Frank A. Chervenak, “Constructing a Systematic Review for Argument-Based Clinical Ethics Literature: The Example of Concealed Medications,” *Journal of Medicine and Philosophy* 32, no. 1 (2007): 74; Maartje Schermer, “Nothing but the Truth? On Truth and Deception in Dementia Care,” *Bioethics* 21, no. 1 (January 2007): 13–22.

that the conflict arises between a multiplicity of values when considering deception in caregiving.

I will reject both the Autonomy and Trust Accounts, as they do not adequately address cases that involve patients who lack mental capacity. For example, the Autonomy Account often focuses on arguing that deception is either morally unacceptable because it violates autonomy or deception can be good despite violating autonomy and it does not capture the interesting non-autonomous cases (for the specific treatment decision) that are most challenging. I will argue that a much more comprehensive account, including the conflict between a multiplicity of values, is needed to morally justify deception in caregiving, taking into account this patient population. In this chapter, I will first discuss what is meant by *beneficence* in bioethics. I will then present both the Autonomy and Trust Accounts, providing reasons why I believe they are alone inadequate to provide moral justification for or against the use of deception in caregiving.

### *Beneficence*

Beneficence is often defined in terms of the *patient's good* or the *patient's best interests*. I will use these terms interchangeably. Caregivers often enter into the caregiving role because they want to see a patient or loved one thrive and do well, given their circumstances. Nevertheless, what is considered as the patient's good can be different from what the patient actually wants or would want if able to exercise his or her own autonomy. Hence, how the *patient's good* is defined will determine if there is in fact a conflict for the Autonomy Account.

Pellegrino and Thomasma argue that acting in the patient's good reflects the patient's desires and values, and they argue that in doing so, one is respecting the patient's authentic autonomy; hence, beneficence is merely an extension of respect for autonomy. I do not think

that this description of beneficence adequately captures the concept, but I will describe this position and explain my reservations. They remark: “the best interests of the patients are intimately linked with their preferences” from which “are derived our primary duties toward them.”<sup>31</sup> They argue that the patient’s good ought to be defined in terms of a patient’s autonomy. Hence, there would be no real conflict, but rather patient autonomy and beneficence are indistinguishable. If a caregiver acts contrary to the patient’s autonomy, then the caregiver is not acting beneficently, and is rather harming the patient’s autonomy. This view reduces beneficence to autonomy and fails to recognize that a patient’s good can extend beyond the capacity to make one’s own choices. Let me expand further on how beneficence can be defined.

Best interests in the Health Care Consent Act 1996 of Ontario include the known values, wishes, and beliefs of an incapable patient prior to becoming incapable, plus a number of other requirements. These include any incapable wishes, whether the patient’s condition is likely to deteriorate, be maintained or improve with the proposed treatment plan, balancing the risks with any benefits and whether there are any other interventions.<sup>32</sup> Best interests are used when there are no prior expressed capable wishes, but rather a substitute decision-maker is required to make a decision in the patient’s good or interest. If prior wishes are not known, then substitute decision-makers consider the benefit versus risk or harm of various interventions, including no intervention at all. Autonomy is helpful to define what is a benefit or harm in each unique situation. Nonetheless, we can likely agree on some general benefits

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31. Beauchamp and Childress, *Principles of Biomedical Ethics*, 207.

32. Health Care Consent Act.

and harms that many would agree upon. For example, most would likely agree that being in pain is a type of harm.

In contrast to the view presented in the previous paragraphs, the predominant concept of a *patient's good* is defined as what a reasonable person would desire or value, as opposed to what each specific patient autonomously chooses or values.<sup>33</sup> DeGrazia describes a *patient's best interests* as a list of values determined by reasonable persons in society and can be applied to a specific medical decision.<sup>34</sup> Kopelman remarks: "The Best Interests Standard was introduced to give some standing to the interests of incompetent or incapacitated persons independent of their guardian's views."<sup>35</sup> This standard was created for those who lack capacity, and for whom the authentic autonomous wishes are unknown. Nonetheless, the best interest standard can also be used when considering a competent patient, given a shared set of values by reasonable persons. However, it would require much more justification to override a competent person's capable wishes.

Kopelman further notes regarding incapable children that:

Once the threshold has been met of showing that the child is in danger within the guardians' care, the courts apply a second test that I have argued can be couched in terms of the Best Interests Standard because judges then should choose the best available option for the child.<sup>36</sup>

Independent of a specific patient, these are shared values that a reasonable person would hold, and they are generally applied in cases where the patient's wishes are unknown, such as with children whose wishes are not yet known. They ought to be considered in cases even when the

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33. David DeGrazia, "Value Theory and the Best Interests Standard," *Bioethics* 9, no. 1 (1995): 50–61.

34. *Ibid.*

35. Loretta M. Kopelman, "The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages," *The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics* 35, no. 1 (2007): 187.

36. *Ibid.*, 188.

patient's wishes are known, to ensure that an open dialogue has occurred given the benefits of a medical decision.

Beauchamp and Childress also argue that beneficence is a distinct concept from autonomy, as it represents “mercy, kindness, and charity” by making the condition of others better.<sup>37</sup> By making the patient's condition better, they argue for a shared and generally accepted sense of good. Hence, beneficence not only applies to groups of patients for whom their values and wishes are unknown, but also to patients who have substantial autonomy. Consider as an example a patient who wishes to commit suicide. This wish may be completely rational, but one would want to first act beneficently, perhaps many times, to ensure that this is the decision that the patient actually wants (e.g. to ensure the patient does not have depression, has all the supports needed to improve her quality of life, and so forth).<sup>38</sup> Acting beneficently may also include acting beneficently for others in the circle of care; for example, caregivers may be distressed and completely overwhelmed constantly trying to convince their patients to take their medication every day. Beneficence may further take into consideration the compassion fatigue and burnout of caregivers in this instance; both of these conditions can significantly impact the level of care the caregiver is able to provide to the patient. For my thesis, I will consider beneficence as acting in the patient's good, in the shared and generally accepted sense of good that most reasonable people in society would want. I also consider autonomy as a separate (albeit related) factor.

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37. Beauchamp and Childress, *Principles of Biomedical Ethics*, 197.

38. Jonathan Glover, “Suicide and Gambling with Life,” in *Moral Issues*, ed. Jan Narveson (Toronto: Oxford University Press, 1983), 29–37.



### *The Autonomy Account*

There are two major positions regarding autonomy and deception. First, there are those who argue that deception is morally indefensible because it directly violates a patient's autonomy. In most cases, patients are capable of making decisions for themselves. The second position argues that deception in caregiving is morally defensible on grounds that autonomy is a moot point since incapable patients lack autonomy, naturally defaulting to beneficence as the ethical guiding principle. I will discuss both positions in this section and argue that the conflict for those cases which I explore, those involving incapable patients, is much more complex than currently described. Both autonomy and beneficence are important considerations among many values and principles.

In the traditional Autonomy Account, it is argued that deception in caregiving is morally objectionable because beneficence comes into direct conflict with a patient's autonomous wishes. Deception, in general, is considered to be morally indefensible as it directly violates patient autonomy; deception aims at making someone believe something to be true that the deceiver believes to be false. It does not allow patients to exercise their autonomy appropriately, since their decisions are based on false information. Sissela Bok argues that autonomy is directly at stake in deception and lying, and it renders people powerless.<sup>39</sup> Bok also remarks that deceiving others injures the deceived and her choices, as they reflect false information.

Richard Griffith further argues that consent must always be provided before surreptitiously providing medication otherwise it would be a trespass.<sup>40</sup> The conflict that

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39. Sissela Bok, *Lying: Moral Choice in Public and Private Life* (New York: Pantheon Books, 1978), xvii.

40. Griffith, "Managing Medical Compliance," 402.

seemingly occurs in these kinds of cases is between a caregiver's duty to act according to the patient's autonomous wishes, and the caregiver's wish to do good for the patient. Acting in the patient's good can include ensuring that the patient's medication is consumed such that she can reap the benefits of the medication. Beneficence can also include deceiving the patient by telling a patient a lie such that she does not suffer. In the Autonomy Account, the problem of deception in caregiving has been traditionally framed for patients who can make decisions for themselves; they have substantial autonomy. The conflict thus occurs when their autonomous wishes are contrary to what is in the patient's best medical interests from the caregiver perspective.

However, a major concern for the kinds of cases that I am exploring is that a patient has very limited autonomy during a psychotic episode or when suffering from advanced dementia; autonomy is often not substantial and the patient is unable to make substantive decisions for herself. Beneficence is an alternative standard to aid decision-making, unless the previous capable wishes and values of the patient are clearly expressed and known. The traditional Autonomy Account does not adequately address cases of substitute decision-makers deciding on behalf of an incapable patient.

Before directly addressing the Autonomy Account, I will say a few words about prior expressed capable wishes. One ought to also be careful when taking prior expressed capable wishes at face value. Wishes should be interpreted and adapted to new circumstances given the context of a patient's values and life, as there are often multiple unexpected variables involved in medical decision-making given a new context in the medical setting. Taking the time to probe and explore what the previous capable wish actually meant for the patient given her experiences can help enlighten what one ought do. I would argue that a combination between

the patient's previous autonomous wishes and beneficence is a more comprehensive method to explore what should be done in each case. In order to consider what one ought to do to respect autonomy, one should ask the kinds of questions such as: "have you considered option X, and what does that mean to you?" It is only through the lens of considering what others generally in society would want that we can formulate these kinds of questions. Hence, I believe that autonomy and beneficence are distinct, but certainly not mutually exclusive, and both extremely important when aiding medical decision-making to make a truly informed decision.

The traditional Autonomy Account maintains that the conflict that occurs with deception in caregiving is mainly between beneficence and respect for autonomy. Predominantly, authors respond in favour autonomy of when patients have mental capacity, and in favour of beneficence when patients lack mental capacity. However, I believe that these arguments do not adequately reflect the complexity of these cases. I will now discuss some of the major arguments regarding patients who lack mental capacity.

McCullough, Coverdale and Chervenak argue that for cases where patients lack mental capacity the principle of respect for autonomy is redundant. Instead, one ought to consider how deception will impact the professional responsibilities healthcare providers have to their patients. For example, truth-telling, trust and beneficence are at the forefront of decision-making.<sup>41</sup> The relationship between provider and patient is what matters, including doing what is best for the patient while maintaining a positive relationship.

Schermer similarly argues that Alzheimer's patients with advanced dementia cannot be said to have the kind of robust autonomy attributed to the principle of respect for autonomy. She remarks: "So, in the later stages of Alzheimer's, capacities for authentic self-creation and

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41. McCullough, Coverdale, and Chervenak, "Constructing a Systematic Review for Argument-Based Clinical Ethics Literature," 73–74.

manifestation may disappear and autonomy may no longer provide a reason against lying.” Hence, for these cases, some argue that respect for autonomy is not a factor in deciding what one ought to do, but rather beneficence takes over and aims at doing what is best for the patient.<sup>42</sup>

Although I agree that respect for autonomy takes on a different meaning in light of these deception cases with patients who are incapable, I argue that the principle of respect for autonomy maintains a vital role when deciding what one ought to do. For example, in cases where patients suffer from psychotic mental illnesses that prevent them from having decisional autonomy, using deception can positively impact the principle of respect for autonomy by providing medication and sometimes therapy that aims at restoring decisional autonomy. In cases where patients are surreptitiously provided medication, which reduces psychotic episodes and restores mental capacity, then respecting autonomy will play a significant role in decision-making, if even it is solely the goal of the decision.

Another function of respect for autonomy is uncovering the prior wishes and values of a patient. On the one hand, a patient may not want to experience and live with the side-effects of taking anti-psychotic medications and would rather experience the symptoms of the illness, as opposed to these side-effects. For example, some short-term side-effects of anti-psychotic medications can include “drowsiness, restlessness, muscle spasms, tremor, dry mouth, or blurring of vision,” while long term effects may include Tardive dyskinesia and other effects. “Tardive dyskinesia (TD) is a disorder characterized by involuntary movements most often

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42. Schermer, “Nothing but the Truth?,” 13–22.

affecting the mouth, lips and tongue, and sometimes the trunk or other parts of the body such as arms and legs” and weight gain.<sup>43</sup> O’Reilly remarks:

All antipsychotic medication can cause side effects. Some side effects, such as parkinsonism or weight gain, may affect an individual’s quality of life; others, such as the disruption of glucose metabolism and elevation of lipid levels, can actually shorten life. It is hardly surprising that some patients prefer to hear voices than to experience these side effects.<sup>44</sup>

On the other hand, other patients may consider it more valuable to be on the medication. Each individual patient generally has a unique display of symptoms, where some symptoms are more intense and apparent than others. Hence, respect for autonomy might include considering what the patient would have wanted during moments of lucidity or given the patient’s values prior to the illness. Those close to the patient are often important and central for helping to determine the patient’s previous autonomous wishes.

For cases where patients suffer from advanced Alzheimer’s disease, the role of the principle of respect for autonomy is not aimed at restoring autonomy since dementia in these cases involves a progressive decline in cognitive abilities. Instead, respecting autonomy relates to what patients would have wanted during moments of authentic autonomy, such as when the patient was mentally capable. Some may argue that after losing certain psychological capabilities and connections to one’s authentic self, the patient with advanced Alzheimer’s may no longer be considered the same person.<sup>45</sup> Questions of personhood and personal identity become necessary in these cases. These extremely challenging and philosophically interesting

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43. National Institute of Mental Health, “Side Effects of Medications for Schizophrenia,” *Psych Central*, accessed February 25, 2013, <http://psychcentral.com/lib/side-effects-of-medications-for-schizophrenia/000712>.

44. Richard O’Reilly, “Why Are Community Treatment Orders Controversial?,” *Canadian Journal of Psychiatry* 49, no. 9 (September 2004): 582.

45. Derek Parfit, *Reasons and Persons* (Oxford: Clarendon Press, 1984).

topics will not be discussed in detail here.<sup>46</sup> Respect for autonomy in these cases is often taken to be what the patient would have wanted considering the patient's life-long narrative and the values espoused by the patient.

Respect for autonomy may also be important regarding respecting the incapable patient's non-substantial autonomous wishes. Especially for cases where substantial autonomy is unlikely to be restored, such as for the advanced Alzheimer's cases, one might want to consider what the patient (in her current state) would want. For example, consider a patient who previously stated that she would always want to know whether her partner passed away; when told that her partner passed away when she asks after him, the patient becomes severely depressed and is unable to participate in the kinds of activities she formerly enjoyed (e.g. playing games with other patients, and spending time outdoors). She becomes distressed at her caregivers for telling her what happened and expresses she wished she hadn't been told. When she is deceived, she is able to have a much higher quality of life given her other values and wishes.<sup>47</sup> Hence, considering the patient's autonomy can involve respecting her non-substantial autonomous wishes. Most often, guidelines for caregivers suggest that patients should be redirected and, although not directly lied to, focus on the feelings and emotions of the patient at the time and avoid direct discussion about the delusion/hallucination.<sup>48</sup>

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46. Descriptively, many people believe in biological identity, that personhood is essentially tied to a biological body that has systems which function together in a particular way; this is the overwhelming view that is accepted. This biological account, coupled with narrative identity according to DeGrazia (a person's life-long story), is generally what is considered to constitute a person over time.

47. Bendigo Health, "Hallucinations, Delusions and Paranoia: Specific Strategies to Manage Hallucinations, Delusions & Paranoia," *Loddon Mallee Regional Dementia Management Strategy*, accessed January 18, 2015, [http://www.dementiamanagementstrategy.com/Pages/ABC\\_of\\_behaviour\\_management/Management\\_strategies/Hallucinations\\_\\_delusions\\_and\\_paranoia.aspx](http://www.dementiamanagementstrategy.com/Pages/ABC_of_behaviour_management/Management_strategies/Hallucinations__delusions_and_paranoia.aspx).

48. Ibid.

As described in the example above, patients who suffer from advanced Alzheimer's disease may have some wishes and desires that may not reflect substantial autonomy, but perhaps ought to be taken into consideration. The conflict in these kinds of cases is not clearly between a *robust* or *substantial* form of autonomy and beneficence. Rather, the experiential or perhaps more basic desires are what bring the patient satisfaction and happiness at a particular point in the disease progression. These experiential desires are important, and one ought to take them into consideration, although not necessarily follow them, depending on the patient's authentic autonomous values and the weight placed on these previous values.<sup>49</sup>

Thus, respect for autonomy is a morally relevant feature not only for those patients who have mental capacity, but also those cases where patients lack mental capacity. The principle of respect for autonomy can also take many different (or a combination of different) forms when deciding whether it is morally defensible for caregivers to deceive their patients, including restoring autonomous wishes, respecting the authentic substantial values and wishes of a patient and, in other cases, respecting the non-substantial wishes of a patient.

### *The Trust Account*

I argued above that the moral conflict currently associated with deception in caregiving is inadequate regarding the conflict between respect for autonomy and beneficence, given the complexity of these cases. I will now argue that the Trust Account, which describes the conflict between trust and beneficence, is similarly insufficient.

Gilson describes trust as: "...essentially a psychological state. In common understanding, to trust someone else is a voluntary action based on expectations of how others

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49. This discussion steps into the realm of personhood and the question: whose desires ought we follow? (e.g. the pre-dementia patient's or the current patient's), which is beyond the scope of this thesis.

will behave in relation to yourself in the future.”<sup>50</sup> He further remarks: “Trust, therefore, involves an element of risk derived from one individual’s uncertainty regarding the motives, intentions and future actions of another on whom they depend.”<sup>51</sup> Trust in cases of deception in caregiving can be interpreted in various ways and I will explore these various interpretations in this section. However, there are several key components that are common among interpretations. I will briefly describe trust in relation to expectations (building from my earlier discussion), voluntariness, vulnerability and competence.

First, trust is about *expectations* of others and how they will interact with oneself given prior experiences, assumptions and so forth. Baier describes these expectations as being contracts set up with others regarding their interactions; she focuses on typical contracts among competent adults in society, such as a plumber and the client.<sup>52</sup> However, in a caregiving relationship the interaction is a much more delicate one between a patient and her caregiver.

Second, even though Gilson describes trust as *voluntary*, I believe that trust is something that can be either active or passive; it is voluntary in the sense that the person engaged in a trusting relationship is often not being coerced to do so. An example of passive trust is that one can grow to trust someone through their experiences without distinctly reflecting and deciding to trust another person. Passive trust, for example, can be between two childhood friends growing up and learning to trust one another. Active trust, however, may include the decision to trust someone despite prior cases that reveal an untrustworthy character.

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50. Lucy Gilson, “Trust and the Development of Health Care as a Social Institution,” *Social Science and Medicine* 56, no. 7 (April 2003): 1454.

51. *Ibid.*

52. Annette Baier, “Trust and Antitrust,” *Ethics* 96, no. 2 (January 1986): 231–260.



Gilson is also correct in naming the risk and uncertainty associated with trust, which often exposes the *vulnerability* of the person who trusts another. Trust involves handing over or allowing someone to have power over oneself, which can be abused or cherished.<sup>53</sup> Baier adds that another component of trust involves the level of security provided to the person who trusts – it is often quite limited and any recourse after a breach of trust is often challenging, unless engaged in a formal contract.<sup>54</sup>

Jones provides the following definition of trust: “Thus, we should say that trust is optimism about the goodwill and competence of another.”<sup>55</sup> Trust is again about managing expectations that others have a particular positive and compassionate goal in mind. Additionally, trust is about reliability of *competency* and skilfulness of the person one trusts. Jones further remarks that trust is situation and decision-specific and should not be considered globally.<sup>56</sup> Hence, you can trust certain people for certain things, but perhaps not for others.

The following study is an example of the conflict between trust and beneficence in an instance of deception in caregiving. Stroup, Swartz, and Applebaum discuss the results of a study conducted on out-patients with schizophrenia in India (Chennai) from 1999–2000.<sup>57</sup> Patient compliance was measured and it was discovered that out of 148 non-compliant out-patients, at least 50% were administered covert medication at least once by family members.<sup>58</sup>

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53. *Ibid.*, 240.

54. *Ibid.*, 251.

55. Karen Jones, “Trust as an Affective Attitude,” *Ethics* 107, no. 1 (October 1996): 7.

56. *Ibid.*

57. Stroup, Swartz, and Appelbaum, “Concealed Medicines for People with Schizophrenia,” 537–542. For the original study see Tirupati N. Srinivasan and Rangaswamy Thara, “At Issue: Management of Medication Noncompliance in Schizophrenia by the Families in India,” *Schizophrenia Bulletin* 28, no. 3 (2002): 531–535.

58. Srinivasan and Thara, “At Issue,” 531–535.

Despite being resentful toward their family members for covertly administering the medication, the patients voluntarily took their medication after being told what had occurred. In these cases, trust was violated to act in the patients' best interests and arguably (since they continued to take the medication) in accordance with the patients' wishes and authentic autonomy.

Lying and deceiving can leave caregivers feeling as if they are doing something inherently wrong to their patients; lying and deceiving their patients is contrary to caregivers' duty to uphold the truth and can erode important caregiving relationships, including trust. Ahern and Van Tosh describe administering of covert medication as the following:

Surreptitious prescribing violates every tenet of the doctor-patient relationship and is the antithesis of recovery. Desperate but ill-advised caregivers and family members who succumb to this insidious and deceitful practice cannot possibly be doing a service to loved ones. They are party to an unimaginable and fundamental loss of trust.<sup>59</sup>

The authors describe deception in caregiving as violating the caregiver- (doctor-)patient relationship, which leads to a breakdown of trust in this important relationship. Trust is vital for recovery and for patients to feel comfortable continuing to receive care from the caregiver if necessary, as well as returning to the caregiver and other healthcare institutions in future.<sup>60</sup>

Beauchamp and Childress do not consider trust as an independent value or principle, such as respect for autonomy, but rather as a virtue of healthcare providers. Healthcare providers ought to provide care in accordance with the virtue of trustworthiness. Other virtues according to these authors include compassion, integrity, discernment and conscientiousness.<sup>61</sup>

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59. Laurie Ahern and Laura Van Tosh, "Taking Issue: The Irreversible Damage Caused by Surreptitious Prescribing," *Psychiatric Services* 56, no. 4 (April 2005): 383.

60. Katrina Armstrong et al., "Distrust of the Health Care System and Self-Reported Health in the United States," *Journal of General Internal Medicine* 21, no. 4 (April 2006): 716–721.

61. Beauchamp and Childress, *Principles of Biomedical Ethics*, 34.

They remark: “Trustworthiness has the practical outcome of promoting the image of the professional and making health care effective. Nothing is more important in health care organizations than the maintenance of a culture of trust.”<sup>62</sup> Trust is extremely important, if not the most important element, for the patient-caregiver relationship. I certainly agree with this claim, and will argue that trust can take different forms, including truth-telling as well as managing expectations (reliability).

According to Gilson, there are several different kinds of behaviours expected with trust, including openness, reliability, technical competence and concern.<sup>63</sup> I will discuss openness (truth-telling) and reliability, and I will include technical competence and concern with the discussion of reliability in the context of caregiving.

### **Truth-telling**

Let us consider truth-telling. I will explicate the notion of truth-telling in caregiving and its importance for trust in this section, and then provide my own insights for why reliability is equally important in cases of deception in caregiving.

Caregivers have a prima facie duty to be honest with their patients. Part of caregivers’ responsibilities and duties is to provide truthful information to their patients, such that their patients can make informed choices; as noted earlier, informed consent is at the heart of respecting patient autonomy. Truthfulness refers directly to the *openness* component of trust discussed by Gilson. This duty also assumes that patients can understand and process the information. However, consider those patients who lack this ability; I will return to this question shortly.

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62. Ibid., 41.

63. Gilson, “Trust and the Development of Health Care as a Social Institution,” 1454.

Patients with advanced Alzheimer's disease often have difficulty forming trusting relationships due to their illness, which raises the question of whether harming trust is as important in these cases.<sup>64</sup> As mentioned earlier, McCullough, Coverdale, and Chervenak argue that respect for autonomy ought not be a guiding ethical principle for cases involving patients who suffer from advanced Alzheimer's disease (a position that I argued against earlier), but rather beneficence ought to be at the forefront of decisions. I argued above that autonomy can be important as well. However, McCullough, Coverdale, and Chervenak remark:

In such cases, to assert that respect for the patient's autonomy creates an ineluctable constraint on what otherwise would be behavior that is deceitful misunderstands the implications of this ethical principle. This has implications for the trust-argument, because patients with significantly impaired decisional autonomy lack the cognitive apparatus to appreciate a trusting relationship in the first place. In other words, an autonomy-based objection to concealed medication, which was the most frequent objection (but not argument) made, does not succeed.<sup>65</sup>

The authors argue that trust is not an important consideration for these populations, since patients suffering from advanced Alzheimer's disease do not have the capacity to appreciate a trusting relationship. My concern here is that just because this patient population in general may lack the ability to appreciate trusting relationships, does not mean that we have a duty to try to foster at least *some* trust among this population.<sup>66</sup> Williams and Tappen explore the therapeutic relationship between nursing home residents who face the later stages of Alzheimer's disease and their caregivers.<sup>67</sup> Extensive literature demonstrates the importance of

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64. McCullough, Coverdale, and Chervenak, "Constructing a Systematic Review for Argument-Based Clinical Ethics Literature," 73.

65. Ibid.

66. I'd like to look further into this point – perhaps even chat with some healthcare workers about it.

67. Baier, "Trust and Antitrust," 251.

fostering a therapeutic relationship specifically in these kinds of cases. Williams and Tappen remark:

To remain in a state of well-being, individuals with dementia depend on others to nurture and reaffirm them. This reaffirming process involves recognizing that persons with dementia are reaching out for social contact, honoring the attempts with a response, providing empathy for their “shattered state,” collaborating with them to describe their experience, appreciating the needs expressed, sustaining dementia sufferers’ actions, responding to their frame of reference, and “holding” or supporting them through their emotional experiences.<sup>68</sup>

There seems to exist other methods through which trust can be fostered among populations suffering from advanced Alzheimer’s disease, which does not rely on truth-telling, but rather on other forms of trust-building.<sup>69</sup>

Interestingly, much written on therapeutic alliance for patients with Alzheimer’s disease is based on the work by Peplau, who aimed to build this kind of relationship with patients who suffer from chronic, regressed schizophrenia.<sup>70</sup> One can extrapolate that the importance of therapeutic alliance and relationship building to foster trust can apply to many patient populations who lack mental capacity, and perhaps even to those populations who have mental capacity. There are several phases associated with this kind of approach, including: the orientation phase, the working phase and the resolution.<sup>71</sup> Other ways to increase therapeutic alliance include: “forming and maintaining a supportive relationship; being understood; expressing concerns; reducing social isolation; maintaining cognitive and verbal abilities as long as possible; reducing stress and frustration; maintaining dignity; and preserving quality of

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68. Christine L. Williams and Ruth M. Tappen, “Can We Create a Therapeutic Relationship With Nursing Home Residents in the Later Stages of Alzheimer’s Disease?,” *Journal of Psychosocial Nursing and Mental Health Services* 37, no. 3 (March 1999): 1.

69. Bendigo Health, “Hallucinations, Delusions and Paranoia.”

70. Williams and Tappen, “Can We Create a Therapeutic Relationship With Nursing Home Residents in the Later Stages of Alzheimer’s Disease?,” 2.

71. *Ibid.*, 3.

life.”<sup>72</sup> This article reveals that there are ample ways to increase trust among patients who lack capacity, without relying purely on truth-telling. This is not to say that truth-telling isn’t itself important, but that there may be other ways of fostering trust that do not involve truth-telling. Recall earlier the discussion of redirection of patients with hallucinations and delusions, which is arguably a form of deception, but nonetheless a positive way of building trust. The positive engagement with patients fosters a caring and trusting relationship, albeit one that involves deception.

Schermer further raises an interesting point that requires addressing; patients who suffer from advanced Alzheimer’s disease (and this can be extended to other patient populations who lack mental capacity) are unable to appreciate the *truth*.<sup>73</sup> Schermer remarks:

I will argue that what can be called deception, or a lie, changes over the course of dementia because dementia slowly diminishes the capacities one needs to distinguish between truths and falsehoods. Once these capacities are lost, the ability to be lied to is also gone.<sup>74</sup>

Hence, patients who lack mental capacity over time also lack the ability to be deceived, according to Schermer; there comes a time when a patient is unable to understand or appreciate the truth, and deception can no longer occur. The problem of deception, according to Schermer, simply disappears in these cases of advanced dementia.

Consider again the definition of deception. Deception purposefully misleads another person to believe something that one (the deceiver) believes to be false. In cases where patients lack mental capacity and they cannot understand and/or appreciate certain truths, can they nonetheless be subject to deception? People in comas or who have such advanced dementia

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72. Ibid., 3–4.

73. Schermer, “Nothing but the Truth?,” 13–22.

74. Ibid., 14.

that they are unable to hold the kinds of beliefs that are true or false cannot be deceived, because no such beliefs are even possible at the time of deception.

What of those cases where a patient is able to hold a true or false belief, but has difficulty or lacks the ability to accurately discern when a belief is either true or false? In these cases, I would argue that patients could be deceived. They can hold a belief that is true or false, and the deceiver influences (or at least tries to influence) the deceived to hold a belief that the deceiver believes to be false. If the deceiver is successful, then deception has occurred; if not, then attempted deception has occurred. Nonetheless, patients who lack mental capacity who are able to hold true or false beliefs can be deceived. This same argument is not only relevant for Alzheimer's patients, but also for those patients who experience psychosis or lack mental capacity for other reasons.

Schermer further remarks: "New information cannot affect the demented patient's identity, his outlook on life, or his plans and goals anymore. This means that the truth or falsehood of this information loses its significance for the patient."<sup>75</sup> However, in my view, although the patient is unable to create long-lasting goals, the patient may still have temporary interests and be able to appreciate momentary emotions, which can include temporarily feeling distress knowing one's partner has passed away, for example. The truth and falsity of these dwindling beliefs are a significant part of the patient's experience and affect the patient's well-being, contrary to Schermer's claim.

DeGrazia discusses the notion of critical and experiential interests from Ronald Dworkin; the main difference being that critical interests are those that represent the authentic values, desires and preferences of an individual, whilst experiential interests are momentary

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75. Ibid., 16.

and basic interests that are not reflective.<sup>76</sup> Although long-term interests may not be impacted by truth-telling and trust, temporary or short-term interests certainly can be. I have argued that despite lacking mental capacity, the truth or falsity of beliefs can still greatly impact a patient's experience; the use of deception is not a null consideration, but rather it is something that can positively or negatively impact the patient's experience, if the patient can hold true and false beliefs.

In this section, I discussed the importance of truth-telling and trust, and those populations who can be deceived given their ability to hold a true or false belief. I also discussed that distraction and redirection are considered deceptive, yet can foster trust through showing genuine care and concern in the caregiver-patient relationship.

### **Reliability**

I will now turn to the concept of reliability as it relates to trust; this discussion will include reliability with respect to technical competence and concern, as forwarded by Gilson.<sup>77</sup>

Manson and O'Neill describe trust as the following: "It is specifically a matter of relying on what others say; on what they undertake to do; on the truth of their claims; and the reliability of their commitments."<sup>78</sup> The authors focus mainly on trust for speech acts and the truth of their claims; tracking truth is seemingly more important than tracking reliability according to these authors. I have described the importance of openness and truthfulness in caregiving, and now I will focus on reliability.

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76. David DeGrazia, *Human Identity and Bioethics* (Cambridge: Cambridge University Press, 2005), 181.

77. Gilson, "Trust and the Development of Health Care as a Social Institution," 1454.

78. Neil C. Manson and Onora O'Neill, *Rethinking Informed Consent in Bioethics* (Cambridge: Cambridge University Press, 2007), 160.



Despite these authors placing significant emphasis on truth-telling regarding trust, in my view, when a patient lacks mental capacity, trust relies just as much, if not more, on what caregivers do and the reliability of their commitments.

What does reliability mean for patients who lack mental capacity? First, patients desire reliability regarding technical competence. They want to ensure that their caregiver is capable of providing quality care, has the skill and expertise to do so and is also able to exercise discernment when required.<sup>79</sup> David H. Thom conducted a study with the Stanford Trust Study Physicians Palo Alto, California, to determine what encourages trust in the caregiving relationship.<sup>80</sup> Through a series of questionnaires and focus groups, 414 patients responded to the study question of what fosters trust with their physician. Thom concluded that: “Caring and comfort, technical competency, and communication are the physician behaviors most strongly associated with patient trust.”<sup>81</sup>

In a different study conducted by Mechanic and Meyer, the researchers examined various patient populations and explored what elements of trust were important for each group.<sup>82</sup> They surveyed patients with breast cancer, Lyme disease, and mental illness. The patient population with mental illness is much broader than the patient populations that I am exploring, but nonetheless encompasses many of the cases that I am interested in. This population valued confidentiality when discussing trust, due to the enormous stigma

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79. Baier provides the example of a plumber who is providing service for a client who must trust that the plumber is working appropriately, given her lack in understanding of how plumbing actually works. This can be extrapolated to other social contracts, like hiring a mechanic and some aspects of healthcare, like undergoing surgery.

80. David H. Thom, “Physician Behaviors That Predict Patient Trust,” *Journal of Family Practice* 50, no. 4 (April 2001): 323–328.

81. *Ibid.*

82. David Mechanic and Sharon Meyer, “Concepts of Trust Among Patients with Serious Illness,” *Social Science and Medicine* 51, no. 5 (September 2000): 657–668.

surrounding mental illness. They further discussed the value of a physician listening to their concerns around side-effects and addressing those worries.<sup>83</sup> These comments reflect other forms of trust that matter to patients, which can be considered as forms of reliability. Confidentiality ensures that caregivers (in the study, physicians specifically) keep information private from others, unless they are obligated to disclose by law. Being listened to is also a form of reliability, which shows an interest and concern for patients – this will be discussed in the following paragraph.

Reliability further focuses on acting in the patient’s values and best interests to alleviate pain and suffering. Gilson uses the word *concern* to describe trust in this context: “A health care provider is specifically expected to demonstrate impartial concern for the patient’s well-being.”<sup>84</sup> Caregivers are traditionally seen as nurturers and healers; showing concern for the well-being of a patient can refer to beneficence and addressing and fostering the patient’s best interests. As described earlier, showing concern for a patient can include not only the medical best interests of the patient but also a concern for the patient’s specific circumstances, including her values and background. Hence, trust as reliability can also be trust to respect the patient’s authentic autonomy (values and wishes during moments of mental capacity) if these are known, in addition to act in the patient’s best interests.<sup>85</sup> The notion of concern is drawn very broadly as an empathetic way of interacting with patients to include the various kinds of interests that a patient may have.

A patient also trusts that she will not be abandoned or neglected during times when she lacks mental capacity. Instead of wanting to be told the truth at all times, patients may

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83. Ibid., 665.

84. Gilson, “Trust and the Development of Health Care as a Social Institution,” 1454.

85. Catholic Health Alliance of Canada, *Health Ethics Guide*, 3rd ed., 2012.

implicitly form social contracts with caregivers, such that caregivers will act in their best interests.<sup>86</sup> In this instance, reliability relates to how patients are able to trust their caregivers, which does not solely rely on truth-telling. I am not arguing that reliability is alone the morally relevant feature for deception, but rather that truth-telling and reliability are both morally relevant factors to be considered. In some cases, one may have more significance than the other – I will discuss this further in Chapter Four.

Trust is especially important for cases where patients lack mental capacity. When a patient lacks mental capacity, she often feels powerless and is extremely vulnerable.<sup>87</sup> Although this population may be able to hold true or false beliefs, their ability to discern between truth and falsity on their own can often be greatly impaired. They rely on caregivers to assist with determining what is true and what is not; hence, if this trusting relationship is damaged, then this patient population would be even more powerless and vulnerable. Immediately, one can recognize the enormous amount of power the caregiver has over a patient. Additionally, once this relationship is damaged, it is extremely difficult to rebuild trust, especially with a population who finds it difficult to understand and appreciate reasons for one's actions.

The caregiver is in a position where she can do much good for the patient, especially in light of the patient's unique values and wishes (such as living a fulfilling life by being able to exercise her autonomy and live her values if mental capacity is restored). Nonetheless, if the caregiver uses deception and the patient is distressed once she is aware of this, trust can be

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86. Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge: Cambridge University Press, 1997).

87. Robert Johns, "Critical Commentary: Who Decides Now? Protecting and Empowering Vulnerable Adults Who Lose the Capacity to Make Decisions for Themselves," *British Journal of Social Work* 37, no. 3 (April 2007): 557–564.

greatly impeded, if not completely lost. In other cases, using deception may increase trust through reliability where a patient regains mental capacity, knowing that the caregiver has fulfilled her duty to take the necessary means to restore the patient's mental capacity. Hence, it is difficult to determine whether using deception is morally defensible or morally indefensible in these cases regarding trust and its various forms without further specifications.

Reliability as a form of trust need not be at odds with beneficence; in fact, acting reliably is often in accordance with beneficence – a consistent set of agreed upon values for patient well-being. Hence, although truth-telling can directly conflict with beneficence, it may not weigh as heavily as being a reliable caregiver (in some cases restoring autonomy), and trust (as reliability) and beneficence may ultimately support using deception in the kinds of cases I explore.

To summarize, one way in which deception has been considered in bioethics is as a conflict between acting in the patient's best interests and encouraging trust in the caregiving relationship. I argued that this dichotomy is much more complex, as one ought to take into consideration not only truth-telling, but also the reliability of the caregiver to act on the patients' wishes and to perform one's expected duties as a caregiver; the concept of reliability also has many different forms, each of which are extremely important for caregiving.

The two traditional ways of exploring the conflict of deception in caregiving, the Autonomy Account and the Trust Account, do not adequately capture the complexity of deception in caregiving. They focus narrowly on one morally relevant feature of the conflict and present a simplified perspective of where the conflict occurs, and which value or principle takes precedence over others. Where does the conflict actually arise; what is the conflict?

## What is the Conflict?

In my view, deception in caregiving is a very complex and multi-dimensional issue; there are not two conflicting duties, principles or values, but rather there exists a plurality of values and duties that can conflict. All of these values and duties ought to be taken into consideration as morally relevant when determining and reflecting upon what one ought to do. In this section, I will discuss some of these considerations, primarily focusing on the traditional bioethics principles. In Chapter Three, I will consider further factors that can help determine the defensibility of deception in caregiving.

As argued above, respect for autonomy is a primary consideration – determining the specific values of each individual patient and what she would want in the current situation. Beneficence, or acting in the patient’s good from a generally shared standpoint, is also a necessary consideration when the patient’s wishes are unknown; it is also important to consider this list of values when obtaining informed consent. I additionally argued above that trust is important, but in *both* its forms – truth-telling and reliability. In addition to respect for autonomy, beneficence and trust, there are other morally significant considerations, including non-maleficence and justice. For the remainder of this chapter I will focus on the other two standard bioethics principles and how they apply to deception in caregiving. Chapter Three will expand beyond traditional bioethics factors to include other morally relevant features, and in Chapter Four I will present an original framework for assessing and bringing all of the morally relevant features together in decision-making.

Non-maleficence is typically defined as only allowing harms if the benefits are proportionate.<sup>88</sup> In its most basic form, it is known as the principle of *do no harm*. The opposite

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88. Beauchamp and Childress, *Principles of Biomedical Ethics*, 153.

would be providing a treatment where the burdens (or harms) outweigh the benefits – hence, acting in malice. Beauchamp and Childress define harms: “thwarting, defeating or setting back some party’s interests.”<sup>89</sup> The concept of harm defined by *interests* is subjective based on the particular *party*. Harm is also not defined as merely a physical injury, but rather it encompasses the prevention of someone from achieving her interests; the concept of interests can include one’s goals, emotions, psychological well-being and so forth. Non-maleficence is hence partially dependent on the autonomy of the patient. Gillon remarks:

People's perception of harm, like their perception of benefit, is idiosyncratic, an integral part of the way they see themselves and of their life plan. One aspect of people's life plans is what the American lawyer Charles Fried calls their “risk budget”, whereby people decide (however inchoately) the sorts of ends they wish to achieve and the sorts of risks – including risks of death – which they are prepared to take in pursuit of those ends.<sup>90</sup>

Non-maleficence asserts that some harm is justified, when the benefits (in relation to the patient’s interests) are proportionate to the harm.

The caregiver must take into consideration the risk of harm that the patient would be willing to take given the patient’s values and wishes; what are the patient’s interests and would deception cause unnecessary harm to the patient? This becomes difficult especially considering a healthcare organization’s responsibility for patient safety. Consider, for example, a patient suffering from advanced Alzheimer’s disease who lack capacity to make complex decisions and lives in a nursing home; she tends to wander if not supervised. Although the patient authentically values her independence and her ability to take walks off the unit when she pleases, the organization also has a duty to keep her safe. The organization ought to look at ways of allowing the patient more freedom, while balancing the danger that may come from

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89. Ibid., 152.

90. Raanan Gillon, “‘Primum Non Nocere’ and the Principle of Non-Maleficence,” *British Medical Journal* 291, no. 6488 (July 13, 1985): 130–31.

her leaving the unit on her own. Hence, this is a case where respect for autonomy and not harming the patient's interest of independence, ought to be balanced in light of the caregivers' duty to protect the patient. One might also argue that the patient has competing interests that come into conflict, such as the interest to be independent, but also the interest to have a safe place to live. If the patient wanders, these interests come into conflict. Hence, non-maleficence is also a morally relevant feature when considering whether deception is morally defensible in these kinds of cases and there are many different factors, as this case demonstrates that ought to be considered within the concept of harm.

The duty to prevent unjustified harms is complex, since there are often different harms involved in each case. Consider a patient who lacks mental capacity due to chronic schizophrenia, and refuses to take her medication. On the one hand, the harm associated with not taking the medication includes a continuing decline in mental capacity, leading to poor choices or actions which may ultimately cause significant harm to the patient; for example, consider someone living in the community who lacks mental capacity and becomes addicted to street or hard drugs; as her mental capacity continues to decline, she may be involved in selling sexual favours for money to buy drugs, in the process being physically and sexually abused.

On the other hand, taking the medication may produce unwanted side-effects, including those described earlier such as muscle spasms, excessive drowsiness and weight-gain. Additionally, if the patient discovers that she has been deceived, she may be reluctant to return to healthcare organizations for future care or treatment, which can cause significant harm, especially if she suffers from preventable or curable illnesses. There are harms that can occur in either situation, but one must consider and balance (along with the other values) which decision will ultimately be best for the patient, and whether deception in either case would lead

to an overall benefit, given the associated harms for each choice, for the patient. Hence, non-maleficence is an important consideration in the decision procedure.

Issues of justice also play an important role when determining the morally correct course of action regarding deception. Justice in bioethics is often discussed in terms of allocation of scarce resources (including access to care), not only within a hospital, but also at the provincial, national and global levels; for example, how do we fairly distribute resources?<sup>91</sup> Other kinds of issues relating to justice include questions relating to disability – e.g. the right to terminate a pregnancy for a disabled foetus and the right to end one’s life early given a disability that makes doing so oneself, impossible. I will discuss that deception in caregiving impacts resource allocation. I will also argue that one ought to consider carefully notions of vulnerability and disability as morally relevant factors for these kinds of cases.

For the case of deception, resources play a role in non-compliance. The medications that patients ought to take are discarded if they are not consumed, when often medications are considered a scarce resource.<sup>92</sup> Nonetheless, Canadian courts have argued that despite these being very real issues that we ought to consider, what really matters when making treatment choices is the patient’s wishes and values and the expertise of the healthcare team regarding what they can and cannot do for the patient. Numerous court cases have stated that although health care resource allocation is a valid concern, it is not to be a reason for providing inadequate care. In one particular case (*Law Estate v. Simcoe*, 1994) physicians argued in court that they did not order a CT scan due to financial constraints; the patient died from a ruptured aneurism. The judge for the case, Justice Spencer, remarks: “those [budgetary] constraints

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91. Beauchamp and Childress, *Principles of Biomedical Ethics*, 240–287.

92. Griffith, “Managing Medical Compliance,” 402–408.



worked against the patient's interest. That is to be deplored.”<sup>93</sup> The patient’s interests come above all financial considerations, according to Canadian courts.<sup>94</sup> Handelman, for example, argues that resource allocation questions should be determined at the legislative level, and not in the courts for individual cases regarding withdrawing life-sustaining treatment.<sup>95</sup>

If we are not to take into consideration allocation of resources when deciding whether to use deception on a case-by-case level, how ought justice be an important moral factor? Justice also serves to protect those vulnerable populations who are at a disadvantage due to various factors. Beauchamp and Childress remark: “Properties distributed by the lotteries of social and biological life do not provide grounds for morally acceptable discrimination between persons in social allocations if people do not have a fair chance to acquire or overcome these properties.”<sup>96</sup> Consider those patients who are unable to make decisions for themselves, those who lack mental capacity. This patient population is in a very vulnerable position, since their decision-making abilities (regarding treatment) are limited. If there is a way to allow this population (this would not be the case for Alzheimer’s patients if autonomous abilities cannot be restored) to regain their ability to make decisions for themselves it would be just to provide them with a fair opportunity to live the kind of life they would likely value and desire.

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93. Barbara Sibbald, “Is Scarcity of Resources a Valid Legal Defense?,” *Canadian Medical Association Journal* 162, no. 6 (March 21, 2000): 880.

94. Martin McKneally et al., “Bioethics for Clinicians: 13. Resource Allocation,” *Canadian Medical Association* 157, no. 2 (July 15, 1997): 163–167.

95. Mark Handelman, “Consent to Withdrawal of Life Support: What the Supreme Court Said in *Cuthbertson and Rubenfeld v. Rasouli*” (Whaley Estate Litigation, October 18, 2013), [http://whaleyestatelitigation.com/resources/WEL\\_What\\_the\\_Supreme\\_Court\\_Said\\_In\\_Cuthbertson\\_and\\_Rubenfeld\\_v\\_Rasouli.pdf](http://whaleyestatelitigation.com/resources/WEL_What_the_Supreme_Court_Said_In_Cuthbertson_and_Rubenfeld_v_Rasouli.pdf).

96. Beauchamp and Childress, *Principles of Biomedical Ethics*, 248–249.

Norman Daniels argues that healthcare is a very special kind of need. It is not simply a desire or preference to have access to healthcare, but having adequate (or at least some minimal) healthcare is essential for general human functioning.<sup>97</sup> Daniels argues in favour of having minimal healthcare such that we can have the basic opportunities to fulfill the kinds of needs we have as human beings, such as attaining food, shelter, companionship and other relationships.<sup>98</sup> Without proper healthcare, our minds and bodies can be affected in such a way that we cannot attain other basic goods; this is why Daniels argues that healthcare is a unique kind of good, upon which so many other goods are contingent.<sup>99</sup>

Being left in a desolate condition such that one is unable to achieve or at least attempt to attain these goods is unjust since one is not given the opportunity to attain them, according to Daniels.<sup>100</sup> Daniels further remarks: “Impairments of normal species functioning reduce the range of opportunity we have within which to construct life-plans and conceptions of the good we have a reasonable expectation of finding satisfying or happiness-producing.”<sup>101</sup> Those who are in a vulnerable position, such as those who lack mental capacity, especially when autonomous abilities can be restored, are in such a position that they can have the opportunity to make and fulfill basic needs, if they receive treatment (in some cases, by means of deception).

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97. Norman Daniels, “Health-Care Needs and Distributive Justice,” *Philosophy and Public Affairs* 10, no. 2 (Spring 1981): 146–179.

98. *Ibid.*, 153.

99. Norman Daniels, “Justice, Health, and Healthcare,” *The American Journal of Bioethics* 1, no. 2 (Spring 2001): 2–16.

100. *Ibid.*, 153.

101. *Ibid.*, 154.

Justice ought to be a factor when deciding whether deception is morally defensible, since justice requires that vulnerable populations have the opportunity, where possible, to achieve the basic needs described above. Does this mean that we ought to use any means to allow patients to have these opportunities? Most would argue that the ends do not always justify the means – this is where balancing and weighing is important. In what circumstances, and in light of the patient’s autonomy, the importance of trust, non-maleficence and other values and principles, ought we use deception such that a patient can attain these opportunities? Does the patient even value these kinds of opportunities seen as having basic value in general society? In my view, deception may be one method to achieve this opportunity for functioning, but may not always be the best course of action. Hence, one ought to weigh and balance the other morally relevant features of the specific case to determine what one ought to do – I will return to this discussion in Chapter Four.

A similar way to look at opportunities is through creating capabilities. How can we support others to be capable of pursuing the types of goals that they desire? Fadden and Powers are well known for their theory on capabilities and the kinds of good that we ought to allow others to pursue. These include: health, personal security, reasoning, respect, attachment and self-determination.<sup>102</sup> Other authors most noted in this discussion include Nussbaum and Sen. Although Sen is vague in defining specific capabilities, Nussbaum lists the following *central human capabilities*: “life; bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; other species; play; and control over one’s

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102. Ruth Faden Wagley, *Social Justice: The Moral Foundations of Public Health and Health Policy* (Oxford University Press, 2008).

environment.”<sup>103</sup> Nussbaum’s list extends further from Fadden and Powers, yet I believe they cover the same general themes of fairly consistent values. These values are also important and operative when we consider the concept of beneficence and best interests of patients when specific, individualized values and wishes are not known. Hence, these are the kinds of capabilities and opportunities that caregivers can consider and in some cases aim towards, when possible.

Another aspect of justice arises from the concept of vulnerability and vulnerable populations. Vulnerability is often discussed in bioethics in the context of research; for example, how do we ensure that vulnerable populations are not being exploited in research?<sup>104</sup> Beauchamp and Childress remark: “In biomedical ethics, the notion of vulnerability often focuses on a person’s susceptibility, whether as a result of internal or external factors, to inducement or coercion, on the one hand, or to harm, loss or indignity, on the other.”<sup>105</sup> For cases of deceiving those who are mentally incapable, this patient population is extremely susceptible to inducement or coercion, making them a highly vulnerable population. Vulnerable patient populations have also been described as groups that are relatively unable to protect their own interests, often from lacking mental capacity.<sup>106</sup>

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103. Martha Craven Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* (Harvard University Press, 2006), 76–78.

104. Ruth Macklin, “Bioethics, Vulnerability, and Protection,” *Bioethics* 17, no. 5–6 (2003): 472–486.

105. Beauchamp and Childress, *Principles of Biomedical Ethics*, 254. One example that Macklin provides is pharmaceutical companies taking advantage of populations who do not have high levels of education in developing nations; these populations are often eager to enroll in trials with the hope of any benefit, despite there likely being little to no benefit.

106. Council for International Organizations of Medical Sciences and World Health Organization, “International Ethical Guidelines for Biomedical Research Involving Human Subjects,” 2002, 64, [http://www.cioms.ch/publications/layout\\_guide2002.pdf](http://www.cioms.ch/publications/layout_guide2002.pdf).

Being highly vulnerable, this population may be more susceptible to harm, loss or indignity if mistreated by their caregivers. For example, on the one hand, if deception is used to give a patient medication that makes her less agitated, but nonetheless reduces her ability to be as alert and active (what she would prefer given her values) without the medication, one might argue that this is harming the patient, and at the very least an indignity to the patient. In Chapter Three, I will provide more detail regarding the importance of dignity and its consideration when deciding the moral defensibility of deception in caregiving. On the other hand, if the benefits of the use of deception seemingly outweigh the harms, then the patient may also experience harm or indignity by not being given medication surreptitiously or not being told a lie. Hence, there is no easy solution to deception in caregiving and each case will have a variety of morally relevant features, some weighing more than others, dependent on the specific case.

There have also been discussions around the need to *fix* or cure those who are different from societal norms, which has also been the focus of recent literature.<sup>107</sup> On the opposite end of that spectrum is the view that we should be more accepting and welcoming of different levels of needs and capabilities and not actively be pursuing cures and changes. Authors such as Shakespeare, argue that we need to be careful thinking about groups with disabilities as needing to be integrated into society as other would expect.<sup>108</sup>

I completely agree that we cannot label everyone who is different from our perceived societal norms as needing to integrate into society. I've argued above that everyone has unique wants, desires and needs and that they are extremely important. I focus specifically on cases of

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107. Tom Shakespeare, "Debating Disability," *Journal of Medical Ethics* 34, no. 1 (2008): 11–14.

108. *Ibid.*

patients who lack capacity to make specific decisions for themselves, which could include deception as a method of engagement and/or treatment. In light of some of Shakespeare's work, disability can have some extremely positive implications. For example, there are historical examples of those who have had mental illness who have made significant contributions, such as Winston Churchill and Vincent Van Gough. Shakespeare's work is a positive reminder that we need to be cautious when wanting to make people's lives better and imposing our own views of good on others. A patient-centered or individualized approach is much more inclusive and sensitive to individual needs, recognizing the pros and cons of having different abilities and capabilities.

### **Conclusions**

Let me return to the chapter title: what is the conflict? For cases of deception, I have argued that the conflict is multifaceted. The principles of respect for autonomy, beneficence, non-maleficence and justice, as well as trust can come into conflict; not necessarily just conflict between one another, but conflict can also occur within the concepts themselves. For example, conflict may occur between various notions of trust. One may wish to encourage truth-telling, but also be pulled toward the duty to be a reliable caregiver by treating one's patient. Caregivers can have many competing desires and duties when contemplating the use of deception, and caregivers ought not be considered irrational for holding them.<sup>109</sup> Nonetheless, they need to make a decision regarding what is morally defensible, and doing so often means subverting one duty (or several) for another (or others).

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109. Patricia Marino, "On Essentially Conflicting Desires," *The Philosophical Quarterly* 59, no. 235 (April 2009): 274–291.

The conflict that occurs with deception in caregiving will not be the same for each case, but rather unique factors involved in each case will change what the conflict actually is. For example, the autonomous wishes of the patient may align with beneficence (doing good for the patient) and these two principles or duties will not conflict. In this particular case, let us consider that the patient suffers from advanced Alzheimer's disease, the conflict might be between the duty to tell the truth to patients, and the patient's wish to not be told her partner passed away as it causes her too much distress.

For a different case, the autonomous wishes of the patient (for example she expressed that she wanted to be told the truth about her partner's passing away) may directly conflict with doing good and doing no harm for the patient. The patient might be in severe agony when told each day that her loved one passed away and be unable to meaningfully participate in other activities that she values. In this case the conflict may be directly between patient autonomy and beneficence. Hence, the conflict will be different, depending on the specific case.

These two examples of cases are also extremely simplified, whereas many different aspects of the biomedical ethics principles actually come into conflict, as opposed to just one conflicting with another. They may all be part of the dilemma, or there may be a conflict between just two principles and duties or even a conflict within just one of the duties itself. Hence, the response to what is the conflict is extremely complex, and Chapter Three will discuss further reasons we have against or in favour of using deception, which add to the complexity of the dilemma caregivers face when deciding whether it is morally defensible to use deception. Chapter Four will discuss a framework for how we can think through these complex dilemmas.

## Chapter 2

### Alternatives to Deception

Some argue that the conflict between values, as described in the previous chapter, may simply be resolved if caregivers use other alternatives to deception. In Chapter One I argued that for cases of deception in caregiving, there is indeed a conflict between various bioethics values; this results in a complex and multifaceted dilemma for caregivers. In Chapter Two, I will argue that there are several ways to respond to this conflict – I will call these the *alternatives*. I will present each alternative along with its associated concerns. I will then proceed to argue that there may be cases where deception is a more morally justifiable option to these alternatives.

The alternatives that I explore in this chapter include physical restraints, advance care planning and absolute truth-telling. I will discuss each alternative in light of the various biomedical ethics values and principles discussed in the first chapter and compare the moral defensibility with the use of deception. However, in order to fully determine which is the most morally defensible alternative one should utilize the organisational and clinical decision-making frameworks that I provide in Chapter Four. For this current chapter, I will consider alternatives for both patients who lack mental capacity with the ability to restore substantial autonomy, as well as patients whose autonomy cannot be restored; there will be some overlap between these discussions, yet some important differences.

Patients who lack mental capacity and have the ability to restore substantial autonomy generally require some form of treatment, most often in the form of medication. For example, consider a patient who experiences psychosis; by taking her anti-psychotic medication, she can regain autonomous abilities. The SDM consents to the medication, acting in the patient's best interests. Deception in this case might involve hiding the patient's medication in her food.



Consider another example where a patient is thought to be a strong candidate for Electroconvulsive Therapy (ECT). The patient lacks mental capacity and refuses to have an IV inserted (a necessary step for the procedure) because she believes, as a result of her paranoia, that the ECT allows aliens to access her thoughts. Deception in this case may involve telling the patient that the IV is for a simple scan that cannot be done while she is alert.

Deception for cases where patient autonomy cannot be restored includes those cases, for example, where a patient suffers from advanced Alzheimer's disease and wishes to drive her car even though her license has been revoked due to her failing vision. She becomes distraught upon learning that she is losing her vision each time she forgets she cannot drive, and her caregivers consider hiding the keys or informing the patient that the car needs repair.

I will ultimately argue that although the three alternatives may be more morally justifiable in some cases, deception can be the morally appropriate and defensible course of action under certain circumstances. I discuss general scenarios in this chapter from which we can compare various alternatives. In Chapter Four I will provide the framework from which one can actually determine which alternative to choose in light of a specific case.

### **Physical Restraints**

One alternative to deception is physically restraining a patient to administer medication and/or treatment. This process requires staff to physically secure a patient, often by holding the patient down or by the use of straps applied to the wrists and/or ankles. Feng et al. define physical restraints as the following: "Physical restraints are mechanical devices, materials, or equipments which restrict freedom of movement or normal access to one's body."<sup>1</sup> Other forms

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1. Zhanlian Feng et al., "Use of Physical Restraints and Antipsychotic Medications in Nursing Homes: A Cross-National Study," *International Journal of Geriatric Psychiatry* 24, no. 10 (October 2009): 2.

of physical restraints may include being a patient on a locked unit, and/or having a gate-device across a patient's door to his or her room to avoid the patient from leaving (this is common for patients with advanced Alzheimer's disease). Additionally, physical restraints have been used to secure patients who tend to have falls – although there are other methods that are now frequently used, such as mats placed at the bedside and arm bands/alarms to signal whether a patient is moving excessively, or a combination of these. Other forms of restraints include chemical restraints (for example, sedating an aggressive patient with medication) and environmental restraints (for example, having a locked unit such that patients who tend to wander cannot leave without supervision).

Physical restraints are common practice in healthcare (especially mental health), and much of the literature surrounding physical restraints involves patients who are aggressive and escalating.<sup>2</sup> In one study, the average use of physical restraints among residents in Canadian long-term care facilities was 31%.<sup>3</sup> In some cases, deception may not be an option, as time constraints and the situation itself may not permit staff to offer a patient a drink or food with covert medication. There may be ways to deescalate a situation ahead of time to do this. In fact there are many different behavioural interventions that have been researched to show the effectiveness of non-restraint interventions.<sup>4</sup> Thus, to avoid great immediate harms, physical and other forms of restraints may be necessary.

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2. Manuela Jarrett, Len Bowers, and Alan Simpson, "Coerced Medication in Psychiatric Inpatient Care: Literature Review," *Journal of Advanced Nursing* 64, no. 6 (December 2008): 538–548; Feng et al., "Use of Physical Restraints and Antipsychotic Medications in Nursing Homes," 1110–1118; Robert E. McCue et al., "Reducing Restraint Use in a Public Psychiatric Inpatient Service," *The Journal of Behavioral Health Services and Research* 31, no. 2 (April 1, 2004): 217–224.

3. Feng et al., "Use of Physical Restraints and Antipsychotic Medications in Nursing Homes," 13.

4. McCue et al., "Reducing Restraint Use in a Public Psychiatric Inpatient Service," 217–224.

In 2001 the *Patient Restraints Minimization Act* was passed in Ontario to ensure that the least restrictive method possible was used for patients, to minimize the harms associated with restraints.<sup>5</sup> It explicitly states the necessity of having a patient's consent (or SDM's consent when a patient lacks mental capacity); the Act also requires that every institution have a policy to implement the least restrictive alternative when possible. The Act additionally mandates that staff have adequate training and that patients are monitored carefully with respect to quality and safety, among other requirements.<sup>6</sup> Nonetheless, physical restraints are still used in healthcare.

O'Brien and Golding argue that both physical restraints and deception are methods of coercion in mental health.<sup>7</sup> They argue that just because a patient lacks mental capacity does not mean that one ought to assume any beneficent act is morally permissible. Rather, one ought to strive for the least coercive treatment possible. Their conclusion aims at reducing the concerns associated with loss of trust and therapeutic alliance when using coercive methods.

They remark:

If on the other hand we apply the principle of least coercive care, we will avoid cases of unjustified coercion and always be looking at how to avoid or minimize coercion by focusing on how non-coercive interventions can be more beneficial. So, coercion is only justified if the client is incompetent in that situation and the harm caused by coercion is much less than the harm caused by the action they would have chosen if left uncoerced.<sup>8</sup>

O'Brien and Golding's major concern is that coercion is misused for patients who ought not be coerced. They argue that the stigma associated with mental illness and patients lacking

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5. *Patient Restraints Minimization Act*, SO 2001, C. 16, 2001.

6. *Ibid.*

7. Anthony O'Brien and Clinton G. Golding, "Coercion in Mental Healthcare: The Principle of Least Coercive Care," *Journal of Psychiatric and Mental Health Nursing* 10, no. 2 (April 2003): 167–173.

8. *Ibid.*, 172.

substantial autonomy can cause coercion to be used for any situation, regardless of whether deception can be morally justified. Hence, they advocate a harm-reduction model, that coercion more broadly is only justified when the harm associated with not using coercion is greater than if it were used.

In contrast, my argument rests not only on weighing and balancing harm between either using or not using coercion, but rather on a multitude of morally relevant factors. Additional factors include the autonomous wishes of the patient, the implications of trust, the patient's best interests and so forth. Some may argue that all other morally relevant factors can be reduced to some form of harm.<sup>9</sup> For example, a particular decision can harm autonomy and/or trust. However, I will assume that a narrow definition of harm will allow these other values to be considered as distinct; in any case, one must discuss each value separately and how it can be harmed. In addition, on the flipside of harm, one ought to also consider the benefits of a particular option and weigh and balance all of these considerations. I agree with their analysis that deception (and coercion) ought to be used sparingly and only in cases where the benefits outweigh the harms. However, I object to their view that harm is the only consideration. As described above, I believe there are other important factors, including important caregiver-patient relationships and factors such as trust and therapeutic alliance.

Authors Jarrett, Bowers and Simpson performed a literature review on coercion and medication as part of treatment. Forced treatment is typically referred to as physically restraining the patient to administer medication, although some studies involved in the literature review included verbal persuasion, including threats to take away certain benefits, as well as deception. The authors provide three reasons for using coercive (or forced) medication:

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9. Bernard Gert, Charles M. Culver, and K. Danner Clouser, *Bioethics: A Systematic Approach* (Oxford: Oxford University Press, 2006).

(i) the patient was manually restrained and given medication in a psychiatric emergency (i.e. in a situation during which the patient was deemed at risk to themselves and/or others at that moment in time); (ii) the patient was manually restrained and given medication as part of their treatment (e.g. the patient had refused their monthly injection and this was administered under manual restraint); (iii) the patient was coerced into taking medication.<sup>10</sup>

The first reason applies to emergency situations, where it is unlikely (though not impossible) that caregivers may use deception – the lack of time and potential harm resulting from the attempt would not likely justify its use. The second and third reasons for coercive medication involve a regular treatment plan to which an advance directive or a SDM provides consent, which the incapable patient is refusing. The second reason involves physical restraints, and the third involves another form of coercion, which is not clearly defined – I imagine it would include deception and offers of rewards/punishment. In their literature review, the authors discovered that although an incident (e.g. physical aggression) was often the cause of forced medication, there were other situations where medication was given through coerced medication as part of regular treatment.

Greenberg and colleagues note that 43% of the patients they interviewed received forced medication as part of their regular treatment plan, as opposed to being from a unique incident.<sup>11</sup> In a survey conducted by Raboch and colleagues across ten European countries regarding the use of coercive measures for inpatient psychiatric units, they discovered that some form of physical coercion was used among 21% to 59% of patients, although they do not clarify whether it was used for an incident or as part of regular treatment.<sup>12</sup> Hence, forced

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10. Jarrett, Bowers, and Simpson, “Coerced Medication in Psychiatric Inpatient Care,” 540.

11. William Greenberg, Lanna Moore-Duncan, and Robin Herron, “Patients’ Attitudes toward Having Been Forcibly Medicated,” *The Bulletin of the American Academy of Psychiatry and the Law* 24, no. 4 (1996): 513–524.

12. Jiri Raboch et al., “Use of Coercive Measures During Involuntary Hospitalization: Findings from Ten European Countries,” *Psychiatric Services* 61, no. 10 (October 2010): 1012–1017.

treatment is common for both incident-related events as well as for regular treatment of this patient population.

In Chapter One, I discussed some of the major concerns and benefits associated with the use of deception in relation to the biomedical ethics principles advocated by Beauchamp and Childress. I additionally considered the various factors relevant to each principle and the importance of trust. I argued in Chapter One that there exists a moral conflict between different values for these kinds of cases. I will now discuss whether we can morally justify the use of physical restraints in relation to the biomedical ethics principles as an alternative to deception in the kinds of cases that I've described as a potential resolution for this dilemma. I will ultimately argue that deception can be a morally preferable alternative in certain cases.

First, let us consider respect for autonomy and physical restraints. Many (if not most) patients who are physically restrained lack substantial autonomy; they are unable to understand and/or appreciate the proposed treatment. Whether physically restrained or deceived (e.g. through covert medication or lying), the aim is that this patient population could regain substantial autonomy, for those who require medication/treatment to do so, or be sustained and maintained at a good level. The method could vary to attain the objective, but the goal would be the same. Hence, this patient population would have the same ultimate aim regarding respect for autonomy and beneficence whether using physical restraints or deception.

Nonetheless, there is an important difference between using physical restraints and using deception and this lies in the means for attaining the same goal or end. Using physical restraints takes away almost *all* autonomy. The patient is rendered completely powerless and unable to exercise most forms of autonomy (not only to make a decision around medication, but also to move and make other decisions) in this position, at least temporarily. As mentioned

above, there may be circumstances when an incident is occurring (such as the patient is violent and other methods to de-escalate have been unsuccessful) and it may be necessary as a last resort to use physical restraints. However, consider a non-aggressive patient who refuses medication and is physically restrained to have medication administered. There is often time to consider other methods to ensure that the patient takes her medication. When using covert medication, the patient retains much of her non-substantial autonomy, still being able to have the freedom to move around and complete other tasks.

How does retaining non-substantial autonomy impact the patient? Having some autonomy gives the patient some power and a feeling of having some control over one's self. At a time when patients are extremely vulnerable suffering from psychosis, retaining some autonomy empowers patients, if even to a small degree. Closely related to respecting autonomy is having dignity. Allowing patients the seeming small freedom to feed themselves and having the freedom to walk on the unit unhindered, treats patients in a dignified manner. Being physically strapped down and unable to fulfill basic needs oneself, arguably makes patients feel undignified.<sup>13</sup> I will discuss this further when exploring non-maleficence.

Regarding beneficence, using physical restraints has the ultimate goal of doing good for the patient – ensuring the patient takes medication that will allow the patient to regain substantial autonomy and no longer be in a psychotic state; when substantial autonomy is regained, the patient can once again meaningfully pursue her goals. Hence, one could argue that using physical restraints (if looking solely at the result of the patient receiving medication) is acting beneficently.

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13. Gwen Bonner et al., "Trauma for All: A Pilot Study of the Subjective Experience of Physical Restraint for Mental Health Inpatients and Staff in the UK," *Journal of Psychiatric and Mental Health Nursing* 9, no. 4 (August 2002): 465–473.

A study exploring views of nurses working on secure psychiatric units in England and Wales, reported that: “Whilst most nurses (n = 259, 96.3%) reported positive outcomes in so far that the incident was brought under control, the views of the aftereffects of the procedure were of concern and ambivalence.”<sup>14</sup> What other effects of using the process of physical restraints cause concern? Does using restraints violate or accord with that of the biomedical ethics principle of non-maleficence (do no harm)?

Let us consider the harms associated with physical restraints and whether they violate the principle of non-maleficence. The National Alliance on Mental Illness (NAMI) produced a report in 1998 indicating the number and nature of events on recent and past abuses related to restraints and seclusion, including deaths, in the District of Columbia over the past five years.<sup>15</sup>

Taxis remarks:

The U.S. Department of Health and Human Services (1992) estimates that at least 100 patients die each year in association with the use of restraints. In 1999 the *Hartford Courant*, a newspaper in Hartford, Connecticut, printed a series of articles regarding the maltreatment and deaths resultant from patient restraint and seclusion.<sup>16</sup>

This series of articles resulted in the NAMI report. The report includes incidents such as patients being left for hours, often urinating on and defecating themselves and receiving injuries through being unattended.<sup>17</sup> These concerns may not be representative of the idea of

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14. Soo Lee et al., “Views of Nursing Staff on the Use of Physical Restraint,” *Journal of Psychiatric and Mental Health Nursing* 10, no. 4 (August 2003): 425.

15. National Alliance on Mental Illness, “Cries of Anguish: A Summary of Reports of Restraints and Seclusion Abuse Received since the October 1998 Investigation by the Hartford Courant,” March 2000, [http://www2.nami.org/Content/ContentGroups/E-News/20013/February\\_20012/A\\_Summary\\_of\\_Reports\\_of\\_Restraints\\_andamp\\_\\_Seclusion\\_Abuse\\_Received\\_Since\\_the\\_October\\_1998\\_Investiga.htm](http://www2.nami.org/Content/ContentGroups/E-News/20013/February_20012/A_Summary_of_Reports_of_Restraints_andamp__Seclusion_Abuse_Received_Since_the_October_1998_Investiga.htm).

16. Carole Taxis, “Ethics and Praxis: Alternative Strategies to Physical Restraint and Seclusion in a Psychiatric Setting,” *Issues in Mental Health Nursing* 23, no. 2 (March 2002): 158.

17. National Alliance on Mental Illness, “Cries of Anguish.”



using restraints – for example, one might argue that if physical restraints are managed better, they might be more effective than other methods; these are perhaps isolated incidents that do not reflect the benefits of using restraints. Granted that these are possible outliers of physical restraints, let us explore general implications for using restraints. First, there are several guidelines from the Registered Nurses Association of Ontario in a comprehensive document to help guide nurses through considering the use of restraints and/ or seclusion.<sup>18</sup> These kinds of standards are in place to reduce the risk of neglect, harm and even death associated with physical restraints; whether they can reasonably be managed due to limited healthcare resources is a challenge many organizations face.

Let us further explore some general harms of using physical restraints. One consequence of using physical restraints is potential injury to either or both the patient and staff. 269 nurses in England and Wales completed a survey working on 63 randomly selected regular secure wards or psychiatric intensive care units on their perceptions of the use of physical restraints.<sup>19</sup> 13% of patients had sustained physical injuries, and 21.6% of staff had been hurt. Injuries included: “‘a black eye’, ‘injured back’, ‘bruised ribs’, ‘broken nose’ and ‘dislocated arm’. Minor injuries included ‘mainly scratches’, ‘grazed skin’ and ‘bruises’.”<sup>20</sup> One might consider that these injuries and harms are proportionate in certain cases; consider for example the patient who is aggressive and no other measures will reasonably protect the patient and staff from harm in an immediate incident.

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18. Laura M. Wagner and Athina Perivolaris, “Promoting Safety: Alternative Approaches to the Use of Restraints” (Registered Nurses’ Association of Ontario, February 2012), [http://www.abinetwork.ca/uploads/Image/8324\\_Promoting\\_Safety\\_-\\_Alternative\\_Approaches\\_to\\_the\\_Use\\_of\\_Restraints.pdf](http://www.abinetwork.ca/uploads/Image/8324_Promoting_Safety_-_Alternative_Approaches_to_the_Use_of_Restraints.pdf).

19. Lee et al., “Views of Nursing Staff on the Use of Physical Restraint,” 425–430.

20. Ibid., 426–427.

In another study by Bonner and colleagues, they examined six incidents that occurred on various psychiatric inpatient units in the UK.<sup>21</sup> The researchers interviewed both patients and caregivers soon after the incident regarding their experiences before, during and after the incident. Patients are often extremely fearful and embarrassed after having been restrained.<sup>22</sup> Nurses expressed how physically restraining patients make them feel as if they had failed and it is only a last resort. Both patients and staff reported feeling distressed and uncomfortable with the incident, mainly from not being able to manage the event prior to it occurring. Both groups felt “low” and “degraded.”<sup>23</sup> Staff also described this experience as being “unpleasant” and “undignified.”<sup>24</sup> Some further issues included that patients were afraid to seek future medical attention after being discharged, in case they would be restrained again.

Being restrained was also particularly difficult for patients who had experienced trauma in the past (in one incident a patient had formerly been raped and, in another, the patient had been abused); the harms associated with the use of physical restraints were intensified since this experience felt like reliving the past trauma.<sup>25</sup> Smith interviewed several patients who had been victims of rape, who were placed into physical restraints. She remarks: “Each person in the case examples speaks of experiencing a betrayal of trust, as well as a determination to never again seek help, preferring to face death rather than the possibility of restraints.”<sup>26</sup> These negative feelings and interactions inevitably impact the level of trust between the caregivers

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21. Bonner et al., “Trauma for All,” 465–473.

22. Ibid., 468.

23. Ibid., 469.

24. Ibid., 469.

25. Ibid., 470.

26. Stephen B. Smith, “Restraints: Retraumatization for Rape Victims?,” *Journal of Psychosocial Nursing and Mental Health Services* 33, no. 7 (July 1995): 26.

and patients. Patients are reluctant to seek future treatment due to the fear of being humiliated and feeling undignified, as well as the risk of reliving traumatic past experiences.

Several other patients experienced physical restraints as follows:

As one 72-year-old man recounted, ‘I felt like I was nobody, that I was dirt. It makes me cry to talk about it’. The feeling of belittlement and shame was echoed in the account of an 84-year-old woman who said: ‘I was embarrassed, like a child placed in a corner for being bad – I haven't forgotten the pain and the indignity of being tied [down]’.<sup>27</sup>

Hence, there are many physical and psychological harms associated with the use of physical restraints, which is why healthcare organizations across Ontario are implementing least restraints policies.

A further consideration when comparing physical restraints is that of justice. Justice, as described in Chapter One, concerns providing opportunities to those who are vulnerable. In both cases of physical restraints and deception the aim, as mentioned above, is to restore substantial autonomy through providing medication and treatment (with the consent given from the SDM) or to prevent grave suffering of the patient whose autonomy cannot be restored.

Another way to consider justice in these cases is through proportionality. Does the means used to achieve restored autonomy justify the ends? The response to this question will depend heavily on the situation; I argued above that in some cases physical restraints is a proportionate response to an aggressive patient, after all forms of de-escalation and alternatives have been exhausted or if there is simply not enough time to try other methods. In other cases, however, the risks associated with deception may be significantly less than the benefits, and deception could be a morally justifiable and appropriate response, again, once other

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27. Serge Gauthier and Antoine Leuzy, “Ethical Issues in Alzheimer’s Disease: An Overview,” *Expert Review of Neurotherapeutics* 12, no. 5 (2012): 557.

alternatives are also explored. It is plausible to consider that there may be situations when deception is more morally defensible than physical restraints. The decision frameworks I present in Chapter Four will help to determine in each specific case which alternative is most morally justified. The populations that I examine are also extremely vulnerable and treating these patients with careful consideration and compassion is also important.

I have argued that substantial autonomy can ultimately be increased for both deception and physical restraints, yet deception allows for non-substantial autonomy to be exercised during this process, while physical restraints takes away almost all forms of autonomy. I further argued that both deception and physical restraints have the same result of acting in the patient's good, to have patients restore substantial autonomy such that they can create and hopefully attain meaningful goals.

Nonetheless, acting in the patient's good in such a way that reduces the amount of harm experienced, obliges us to choose the method that results in the least harm of the patient. For example, will using physical restraints or using deception have a significant impact on the patient returning for care in future? How does each of the options impact the trust relations between the patient and the caregiver? I also argued that the kind of harm (including harm to trust) that results from the physical restraints can be disproportionate to the immediate benefits of taking medication – this may also be the case with using deception. It is important to explore for each case which alternative would likely produce the greatest benefit compared to the harms endured.

One must also consider the long-term impact of using physical restraints versus using deception. Would a patient likely be harmed more from the physical administration of treatment (losing complete autonomy), or from knowing that she was psychologically deceived

into taking the medication (the feeling of being tricked by the caregiver)? There is a strong emphasis on the impact of each alternative on each specific patient. There also exists an epistemological question of: how do we know how the patient will react to the specific method? This may be easily determined given a long-standing relationship with a patient or perhaps given clearly written advance care directives. However, in other cases, one might argue that the risk would be much higher if the reaction of the patient can be less likely estimated. Deception involves estimating risk of future harm to the patient – I will return to this concept in Chapter Four, when I discuss how one weighs and balances the morally relevant features.

I advocate for a patient-centered approach; this means that the history and the circumstances of the specific patient will influence the degree to which each factor matters when balancing and weighing what one ought to do. Lipkin and colleagues were one of the first to define patient-centeredness; they describe that a patient-centeredness interview:

...approaches the patient as a unique human being with his own story to tell, promotes trust and confidence, clarifies and characterizes the patient's symptoms and concerns, generates and tests many hypotheses that may include biological and psychosocial dimensions of illness, and creates the basis for an ongoing relationship.<sup>28</sup>

For example, if a patient has formerly been a victim of rape, then caregivers need to be much more sensitive when determining whether physical restraints or deception is the best course of action – it is also important to note that this information is not always readily available to caregivers, as described above, being an epistemological concern.<sup>29</sup> McWhinney similarly

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28. Mack Lipnik Jr., Timothy E. Quill, and Rudolph J. Napodano, "The Medical Interview: A Core Curriculum for Residencies in Internal Medicine," *Annals of Internal Medicine* 100, no. 2 (February 1, 1984): 277–284.

29. Note: this raises the issue: should we always veer on the side of caution, if there are so many unknowns?

summarizes the notion of patient-centeredness such that a: “physician tries to enter the patient’s world, to see the illness through the patient’s eyes.”<sup>30</sup> Much of the concepts of harm, values, benefits and so forth ought to be viewed from a particular position – given the context from which a patient comes.<sup>31</sup>

Physical restraints may also be used for patients whose autonomy will not be restored, such as patients who suffer from advanced Alzheimer’s disease. As described earlier in this chapter, the use of physical restraints is quite prevalent in nursing homes in Canada. The Alzheimer’s patient population often has the following symptoms associated with the disease: “muscular weakness; history of falls; visual, gait, and balance deficits; impaired functioning; depression; and cognitive impairment.”<sup>32</sup> These symptoms increase the risks and harms associated with this patient population especially for both falls and wandering; additionally, these symptoms also increase the risk of physical harms that can occur from physically restraining a patient in this condition.

In some cases, being on locked units and being environmentally restrained does not cause patients distress. However, sometimes this process can be extremely traumatizing to the patient, feeling like a prisoner and having less control over one’s autonomy and self. Hamers and Huizing conducted a literature review on the prevalence of the use of forms of physical restraints for elderly populations and concluded that: “Physical restraints are still highly prevalent in health care settings in many countries. Between 1999 and 2004 reported

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30. Ian Renwick McWhinney, “Are We on the Brink of a Major Transformation of Clinical Method?,” *CMAJ: Canadian Medical Association Journal* 135, no. 8 (October 15, 1986): 876.

31. This notion becomes particularly challenging for cases involving children and the values of their parents, as well as for patients whose baseline is already incredibly low – for example, they’ve been living with sores and infections on the streets their entire lives.

32. Jane Tilley and Peter Reed, “Falls, Wandering and Physical Restraints: Interventions for Residents with Dementia in Assisted Living and Nursing Homes,” *Alzheimer’s Association*, August 2006, 4, [http://www.alz.org/documents/national/Fallsrestraints\\_litereview\\_II.pdf](http://www.alz.org/documents/national/Fallsrestraints_litereview_II.pdf).

prevalence numbers range from 41–64% in nursing homes and 33–68% in hospitals.”<sup>33</sup> The main reason for using physical restraints is patient safety – to prevent falls, patients from interfering with medical equipment (e.g. if the patient is cognitively impaired) and patients from wandering.<sup>34</sup>

In some cases, the degree to which the patient suffers from Alzheimer’s disease may be so severe that deception is not an option. As described in Chapter One, if a patient is unable to hold a true or false belief, then deception does not occur. In these cases, the use of physical restraints and its alternatives may be warranted – although there are current developments regarding less-restrictive alternatives, such as patch alarms that monitor patient movement and the alarm sounds when the patient is likely to harm his/herself, for example with excessive movement increasing the likelihood of falls. Often when the alarm sounds, the patient refrains from continuing to move. A significant concern, however, to keep in mind is that with limited healthcare resources, in healthcare organizations the response time for a room call may increase as staffing issues become more prevalent.

The Registered Nurses Association of Ontario discusses several strategies for nurses, which focuses on prevention and alternative approaches, deescalating and crisis management to finally considering restraints (and other forms of coercion) as a last resort.<sup>35</sup> Several examples of alternatives include: explanation and reminders, distraction and diversion,

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33. Jan Hamers and Anna R. Huizing, “Why Do We Use Physical Restraints in the Elderly?,” *Zeitschrift Für Gerontologie Und Geriatrie* 38, no. 1 (February 2005): 22.

34. Ibid.

35. Registered Nurses Association of Ontario, “Promoting Safety: Alternative Approaches to the Use of Restraints,” February 2012, 20, [http://rnao.ca/sites/rnao-ca/files/Promoting\\_Safety\\_-\\_Alternative\\_Approaches\\_to\\_the\\_Use\\_of\\_Restraints\\_0.pdf](http://rnao.ca/sites/rnao-ca/files/Promoting_Safety_-_Alternative_Approaches_to_the_Use_of_Restraints_0.pdf).

camouflage, comfort and positioning, technologic reduction and environment.<sup>36</sup> Other alternative methods include encouraging family members or volunteers to spend time with the patient during “high risk” times and having large “stop” or “exit” signs at each exit to remind patients to not leave, for example.<sup>37</sup>

Consider the cases where a patient can hold true and false beliefs. For how long can the patient hold these beliefs? If the patient can only hold these beliefs for an hour, then will continue to wander or be at risk again for a fall, it may be unreasonable for a caregiver to return to the patient every hour and restate the deceptive claim. This is again why I advocate a patient-centered approach, being sensitive to each unique patient’s situation, since each patient will have different needs based on numerous factors, including the level of his/her cognitive impairment, his/her background of trust with healthcare institutions (and perhaps their physician) and so forth. Hence, it is not clear that either physical restraints or deception is clearly the most morally defensible option, and each case ought to be explored carefully. I will further outline these specific factors in Chapter Four.

For patients who are able to hold true and false beliefs for a reasonable period of time, deception could be considered a treatment option. In what cases would deception be morally defensible, and the use of physical restraints unwarranted? I have argued above that there are significant risks associated with the use of physical restraints that deception does not incur, or incurs to a lesser degree than physical restraints. In cases where deception is possible (e.g. cognitively and due to available time), it could be considered as an alternative to physical

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36. Ibid., 32–33.

37. Bendigo Health, “Alternatives to Restraint,” *Loddon Mallee Regional Dementia Management Strategy*, accessed March 16, 2013, [http://www.dementiamanagementstrategy.com/Pages/ABC\\_of\\_behaviour\\_management/Management\\_strategies/Alternatives\\_to\\_restraint.aspx](http://www.dementiamanagementstrategy.com/Pages/ABC_of_behaviour_management/Management_strategies/Alternatives_to_restraint.aspx).



restraints, but should endure the framework I develop in Chapter Four to determine which alternative is most morally defensible in this patient-centred model.

In the cases of patients who suffer from advanced Alzheimer's disease, substantial autonomy will not be restored, contrary to those cases where patients can take medication to do so. How might deception be more conducive to respect for autonomy than physical restraints? Deception allows patients to still conduct much of their daily activities as usual, for example, being able to easily pick up a book or reach for a drink; physical restraints place enormous restrictions on most daily activities of this patient population. I do not argue that deception ought always be used rather than physical restraints, but deception can be morally defensible compared to physical restraints in certain cases.

The principle of beneficence aims at acting in the patient's best interests. As argued above, both physical restraints and deception have the goal of benefitting the patient and enabling the patient to live a fulfilling life. Is one more conducive to acting in the patient's good than the other? If one method can achieve this goal better than the other, of encouraging patients who suffer from advanced Alzheimer's disease to take their medication when they refuse to, then this method ought to be used. For example, causing a patient less distress in the process is better than increasing potential harm while achieving the desired end.

I have discussed extensively the harms associated with physical restraints; the harms that stem from deception are often considered to be damaged trust. Although there is not too much evidence or research on the effects of deception, the study on out-patients in Chennai that I presented in Chapter One, reveals that although trust was damaged between caregivers and patients, patients continued to take their medication after discovering that deception

occurred.<sup>38</sup> Deception can impede trust relations if the patient is aware that she has been deceived. Once trust is broken, it is difficult to rebuild. The same can be argued for physical restraints, except that trust is perhaps more likely to be broken in these cases, since the patient is completely aware that she is being restrained, whereas deception is much more subtle and disclosure of what happened occurs when the patient is more stable – such as once he or she regains mental capacity, for those who can.

I have discussed the alternative of physical restraints in great detail, and how each of the biomedical ethics principles, as well as trust, can be applied when using this method. I argued that the use of deception can be a morally preferable method to physical restraints in certain cases, when considering non-substantial autonomy enhancement, increased trust, non-maleficence, beneficence and justice. Each of these factors is an important consideration and I do not argue for solely a harm-reduction approach more broadly, but rather build on several different factors to enhance autonomy, well-being and the caregiver-patient relationship. The circumstances will greatly inform whether the situation requires and provides moral justification for either physical restraints or deception and I will return to this notion in Chapter Four; however, I have argued that deception may be more morally justifiable compared to the alternative of physical restraints on some occasions.

### **Advance Care Planning**

Another alternative to deception is participating in advance care planning (ACP) regarding the kind of treatment one would want for future medical situations. ACP involves considering one's values, wishes and beliefs in light of medical decisions that may arise in future. ACP can

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38. Stroup, Swartz, and Appelbaum, "Concealed Medicines for People with Schizophrenia," 537–542. For the original study see Srinivasan and Thara, "At Issue," 531–535.

be as simple as discussing one's preferences with family members and friends, to creating a formal advance care directive. Palliative Care Australia describes ACP as:

...a process to help people to formulate and communicate their preferences regarding care during future incapacity. Advance care planning gives the person the opportunity to determine the likely scenarios coming towards the end of their lives, including the treatment they receive and the way they would like to be cared for.<sup>39</sup>

The Canadian Hospice Palliative Care Association created a campaign called "Speak Up" that illuminates the process of ACP.<sup>40</sup> The kinds of questions present in an ACP can include: "If possible, would I prefer to die at home, in a hospice or in the hospital? What might change my mind about my choice?" and "Do I have any fears about dying (e.g. I'll be in pain, I won't be able to breathe)? Is there someone that I can talk to about these fears, such as my doctor?"<sup>41</sup> Ideally, ACP is a way of communicating one's wishes such that when a person loses mental capacity and at the time of difficult situations and decisions, the substitute decision-maker(s) has a good idea of what the patient would want. ACP has many different facets, which may include discussing one's values, wishes and personal care choices and choosing a substitute decision maker. Choosing a substitute decision-maker in Ontario is completed through a Power of Attorney for Personal Care document. However, I will focus on the values, wishes and beliefs indicated in an ACP and the various forms that this can take.

One method of ACP is creating an advance directive (AD), which includes general guidelines for a substitute decision-maker to interpret around future decisions when a person is no longer capable to make decisions for his/herself. ADs are often vague and brief, and still

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39. Palliative Care Australia, "Advance Care Planning: Interim Position Statement," December 2008, <http://www.palliativecare.org.au/Portals/46/Policy/PCA%20Advance%20Care%20Planning%20Position%20Statement.pdf>.

40. Canadian Hospice Palliative Care Association, *Speak Up*, 2015, <http://www.advancecareplanning.ca>.

41. Ibid.

require input from SDMs. A Ulysses contract, a kind of AD, is based on the ancient Greek story of the great warrior and captain Ulysses (or Odysseus). During his journey home from a quest, Ulysses and his crew pass through a sea where they encounter beautiful Sirens; these mythical creatures have remarkable singing voices that lure sailors such that they no longer have any thinking or reasoning abilities. The sailors hence crash their ships on the rocks and the Sirens consume their bodies. Ulysses is aware of the influence of the Sirens and he forms a contract with his crew. He orders them to place wax in their ears such that they cannot hear the Sirens' songs, and to tie him to the mast. Ulysses anticipates that he will lose his reasoning abilities once he hears the Sirens' song and tells his crew to not untie him during their voyage through the sea, despite him pleading and ordering them to do so. Essentially the contract represents his wishes when he has a sound mind, in anticipation for when he no longer has mental capacity, such that his wishes will continue to be fulfilled. Ulysses' prediction was correct, and the crew did not untie him, saving his life and that of the crew by following his previously expressed wishes.<sup>42</sup>

In healthcare, some forms of ACP adopt the name *Ulysses Contract* based on this story. Individuals who suffer from persistent or chronic mental illnesses form these kinds of contracts in advance, during moments of lucidity, when one has substantial autonomy; Macklin describes when a Ulysses contract is appropriate:

A Ulysses contract is considered appropriate for individuals who suffer from a psychotic disorder that is characterized by intervals of “normalcy” alternating with bouts of acute psychosis. This pattern would establish the utility of the contract and would also ensure periods of lucidity during which a competent consent to the contract could be obtained. The disorder must be relatively

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42. Aaron J. Atsma, “Seirenes,” *Theoi Project Company* (New Zealand, 2011 2010), <http://www.theoi.com/Pontios/Seirenes.html>.

serious (i.e., manic depression, schizophrenia, depression) and must also be amenable to treatment.<sup>43</sup>

When a person relapses, the Ulysses contract invokes certain guidelines and directions as to how to proceed. These contracts could involve discussing whether to allow covert medication during times of mental incapacity.<sup>44</sup>

Similar to a Ulysses contract is a Community Treatment Order (CTO) which is a legal contract under the Ontario Mental Health Act (OMHA); a CTO encourages patients who have persistent mental disorders to return to the community, while having a plan in place to ensure that they receive the treatment that they need and want when unable to make these decisions.<sup>45</sup> These plans help to reduce acute-care facility admissions, as well as to prevent patients from serious relapse. A CTO, like a Ulysses contract, also imposes certain consequences (a CTO is a legal contract) for not conforming to the plan, such as re-admittance to a healthcare facility or forced medication if not complying to the agreed contract. Often local police services are utilized to help enforce these contracts when they are not being followed.

As an alternative to deception, one might argue that ACP could replace the need to consider whether to use deception or other alternatives at the time of a crisis or treatment decision. Patients, during moments of lucidity, could plan in advance the kind of treatment they would want during moments when they lack mental capacity. These kinds of contracts would not require that caregivers decide what is in the best interests of the patient, as the autonomous wishes of patients would be known. A common argument that I have heard

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43. Audrey Macklin, "Bound to Freedom: The Ulysses Contract and the Psychiatric Will," *University of Toronto Faculty of Law Review* 45, no. 1 (Spring 1987): 39.

44. K. S. Latha, "The Noncompliant Patient in Psychiatry: The Case For and Against Covert/Surreptitious Medication," *Mens Sana Monographs* 8, no. 1 (2010): 96–121.

45. A CTO is also referred to as an Involuntary Outpatient Commitment (OPC), or assisted outpatient treatment.

through anecdotal evidence is that if the patients' prior expressed wishes were known, then we would know exactly what to do and there would be no conflict. If we know that they want medication, we provide it, and so forth. However, I will argue that this does not render the dilemma as a non-issue, as ACP may not be a reliable source, can often be very vague and must be interpreted by a substitute decision-maker. Additionally, from a practical standpoint, ACP is currently not often completed.

In this section, I will first argue that ACP itself is controversial as a source of decision-making authority. In addition, if even ACP were to be used to help guide decision-making, one ought to still tackle the dilemma of deception, following the same principles and decision-making procedure as if one were currently deciding to use deception. Hence, I argue that ACP can be an alternative to deception, but may often still require that caregivers either consider deception as part of future care planning or address questions of deception where ACP is simply impracticable or impossible.

I will now discuss some concerns with ACP. First, ACP is not well known and poorly implemented. "Less than 50 percent of the severely or terminally ill patients studied had an advance directive in their medical record," according to Kass-Bartelmes and Hughes.<sup>46</sup> Also, "Between 65 and 76 percent of physicians whose patients had an advance directive were not aware that it existed," which indicates that even though they may have been completed, they are not being implemented appropriately.<sup>47</sup> In addition, when creating the ACD, only 12% of patients did so in consultation with a physician.<sup>48</sup> Without having appropriate consultation with

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46. Barbara L. Kass-Bartelmes and Ronda Hughes, "Advance Care Planning: Preferences for Care at the End of Life," *Research in Action*, no. 12 (March 2003): 2.

47. *Ibid.*

48. *Ibid.*, 2.

a physician or other relevant specialists, one may not be fully aware of the medical implications for refusing or consenting to specific procedures and other available alternatives. For example, depending on one's condition, cardio-pulmonary resuscitation (CPR) can result in broken ribs and significant organ damage.

As with the use of physical restraints, one could argue that if ACP were done more appropriately and more frequently with each patient, then ACP would be the best option. However, ACP is probably a step in the right direction, but there are nevertheless several major concerns associated with ACP – not only with completing ACP, but also the feasibility and logistics of its implementation. I will discuss concerns related to both arms. The former, I will call the inherent problem and the latter, the implementation problem. Regarding the implementation problem, I think there are more possibilities for resolving these concerns, whereas the inherent problems are less likely to be resolved. In addition, I will note that when applicable, ACP cannot be completed without having a discussion about deception and its future use as a genuine option for treatment when lacking mental capacity; the use of deception is likely a necessary part of the discussion.

First, let me address the inherent problem. One significant concern with ACP is that it does not cover the vast range of situations that arise; even for those situations that do actually occur, one can only vaguely anticipate what it is like to *actually* experience that situation. It is extremely difficult to imagine oneself in a position of mental incapacity, and to understand the side effects that actually result from taking certain medications (since this is often subjective); it is also challenging to imagine whether one would rather take a medication or not experience these side effects. One patient population where creating an ACP would be most applicable is where they are aware of relapse and how it feels to both be on medication/receiving treatment

including experiencing the side-effects, as well as those times when they are not receiving any form of treatment.

The specific condition and the predicted outcomes associated with each treatment option are highly dependent on the individual when actually in this situation – not to mention co-morbidities and their combined effects on patients. It would be ideal to have these kinds of detailed contracts, but in reality they cannot capture the complexity of situations that arise. Realistically, anticipating and predicting the full range of situations is impossible – we can have a rough sense of a person’s values, but be unable to determine precisely what he/she would want in every situation. ACP ought to be interpreted by a SDM as it relates to a current medical situation.

Judith Wahl describes the challenges of ACP in contrast to making decisions about likely events occurring. For example, in an acute setting, CPR (cardiopulmonary resuscitation) is more likely to be a proposed treatment option with specific consequences and associated harms/benefits, whereas, before one becomes ill, CPR is much more vague and does indicate what kinds of proposed treatments, benefits and risks would arise under various kinds of circumstances. Wahl remarks: “advance care planning is usually much broader in scope and a great deal more speculative as the patient is expressing wishes about future care without full knowledge of his or her present health condition or full knowledge of his or her possible treatment options.”<sup>49</sup> I am not arguing the ACP is ineffective or valueless – I believe it has significant value for *assisting* with making decisions for patients who lack mental capacity.

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49. Judith Wahl, “Advance Care Planning – the Legal Issues” (Canadian Centre for Elder Law Studies Conference, South West Hospice Palliative Care Network, 2006), 3, [http://demo.swpalliativecare.ca/infonetwork\\_docs/AdvanceCarePlanning\\_Legal.pdf](http://demo.swpalliativecare.ca/infonetwork_docs/AdvanceCarePlanning_Legal.pdf).



However, I think ACP needs to be evaluated with a number of other factors, including changes in the patient's wishes in light of how situations actually unfold.

A clear analogy of concerns associated with ACP is that of epidural anaesthesia. Often pregnant women, who describe their preference to not receive an epidural, actually change their minds at the time of giving birth.<sup>50</sup> They were previously unable to anticipate the intensity of the pain when making this advanced choice. Some might argue that the pain of giving birth is not an appropriate time to provide informed consent due to a “change of mind” since the pain disables rational decision-making, rendering a woman incapable of making this decision. However, even though I do agree that pain can interfere with autonomous decision-making, I think at childbirth a woman can still reflect on what she would want given her values and current experience – I don't think childbirth renders a woman significantly incapable of this ability.

Trial periods and taking time to adjust values and goals can be extremely effective in helping those who are struggling with significant changes in their lives to consider a different way of finding meaning and value– this presents a challenge to ACP, unless ACP continuously updated. Furthermore, it highlights that ACP cannot capture the vast array of changes that arise. A study was conducted from a rehabilitation unit in northwest England.<sup>51</sup> Twelve former patients who had suffered from strokes were initially interviewed upon admission, and again after twelve months. The researchers aimed to explore whether the rehab goals of recovery were appropriate considering the patient's experience after leaving the healthcare institution.

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50. Eva Van den Bussche et al., “Why Women Prefer Epidural Analgesia during Childbirth: The Role of Beliefs about Epidural Analgesia and Pain Catastrophizing,” *European Journal of Pain* 11, no. 3 (April 1, 2007): 275–82.

51. Christopher R. Burton, “Living with Stroke: A Phenomenological Study,” *Journal of Advanced Nursing* 3, no. 2 (2000): 301–309.

The researchers discovered that rehab goals are extremely fluid and dependent on the patient's specific values and how the patients find meaning throughout his or her changing and lived experience. The author writes: "This study suggests that stroke is an intensely personal experience, involving the rebuilding and restructuring of an individual's world."<sup>52</sup> Hence, ACP ought to be a guideline, but also fluid enough to represent the changes that can occur in meaning and value of life over time. For example, other patients may initially indicate that they would not want to live in a particular state, whereas upon finding different kinds of meaning (when possible) they are able to continue to find a good quality of life in a different way from previously anticipated.

I will now turn to the implementation problem. First, when completing ACP, wishes are often quite vague. A concern with ACP is that one might say "I would never want X," but actually unpacking what X means might result in a different wish. For example, it is common for patients to say "I would never want to live in long-term care (LTC)" and/or "I just want to return home." If a caregiver, however, was to have a deeper discussion with the patient, such as "what does home mean to you?" his/her choice to not go to a LTC might actually change. Home might mean a place that has a certain degree of privacy, a sense of community, access to one's religious center and so forth, as opposed to a particular location. Wahl remarks:

Some lawyers use stock phrases such as "I don't want extraordinary measures to be used on me" in drafting a written advance care plan, but fail to discuss what the particular client means by that phrase. They don't include the interpretation of that phrase in the drafted document so the document doesn't communicate what the client wanted, or didn't want, in a practical way.<sup>53</sup>

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52. Ibid., 307.

53. Wahl, "Advance Care Planning – the Legal Issues," 4.

When participating in ACP, it is important to capture the patient's values and wishes at a deep level, and to do one's best to not merely accept superficial or unpacked wishes. ACP can have difficulty capturing these kinds of wishes, especially in a check-box form of ACP.

Wahl also describes the challenges of scientific changes that alter the effects and outcomes of certain treatments, perhaps making them acceptable to someone who would have previously refused this kind of treatment.<sup>54</sup> For example, a treatment that would have formerly had much associated pain, may now actually be relatively painless. At the time of participating in ACP, the new procedure simply may have not existed. Hence, ACP needs to be updated regularly and consistently – whether healthcare providers and physicians can realistically do this is a challenging question, as with limited healthcare resources, time and other resources are extremely constrained. Additionally, there is much misinformation in the media and through other social sources that misconstrue and distort our understanding of technology, procedures, practices and also of healthcare more broadly. Consider for example the movie *One Flew Over the Cuckoo's Nest* (1975);<sup>55</sup> this film has negatively influenced the way that many perceive of ECT (Electroconvulsive Therapy) and being a mental health patient in an acute or post-acute setting. However, ECT has changed significantly over the past three decades, being now recognized as an effective form of treatment, with few side effects.<sup>56</sup> Another example is Jenny McCarthy and her opinion that vaccines cause autism.<sup>57</sup> This media sensation has caused much misinformation to be spread in various forms. Without having the appropriate people at the

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54. Ibid.

55. Milos Forman, *One Flew Over the Cuckoo's Nest*, Movie (Fantasy Films, 1975).

56. John Geddes et al., "Efficacy and Safety of Electroconvulsive Therapy in Depressive Disorders: A Systematic Review and Meta-Analysis," *The Lancet* 361, no. 9360 (n.d.): 799–808.

57. "Jenny McCarthy: Report of New Stance on Autism, Vaccines 'Irresponsible and Inaccurate,'" *CTVNews*, accessed March 15, 2015, <http://www.ctvnews.ca/entertainment/jenny-mccarthy-report-of-new-stance-on-autism-vaccines-irresponsible-and-inaccurate-1.1617795>.

table for these conversations, ACP may not actually be completed in an informed manner and could lead to unanticipated harms compared to benefits.

Realistically, another concern with ACP is that caregivers, especially those in a hospital setting, often see individuals when they already lack capacity, which is beyond being able to have these kinds of discussions. Many medical events occur unexpectedly prior to having an in-depth discussion surrounding ACP. Additionally, many Canadians do not have a family doctor and do not have access to someone who can provide the time to have the kind of detailed and informative discussions needed when making ACPs.<sup>58</sup>

I have now discussed several major concerns with ACP and argued that these concerns do not make ACP a clear alternative to using deception, as some may argue. Rather, ACP has significant issues both relating to the inherent and implementation problems. I think that due to the implementation problem, reflection on what one ought to do in these kinds of cases requires an in-depth discussion regarding deception. Additionally, ACP has inherent concerns with being able to accurately predict complex medical situations and the possibility of adapting and changing one's mind. Hence, ACP is not a clear or morally better alternative to deception. Nonetheless, if ACP can be done well, deception ought to be a component of ACP, when possible. When ACP has not been completed, which is the majority of cases due to the inability of resources to make ACP feasible, deception ought to be considered in light of weighing and balancing the bioethics principles, which I will discuss in chapter four. I believe that ACP can be useful, but judgment is necessary for the SDM(s) and the caregiver at the time of the decision to truly capture what the patient would want.

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58. "Access to a Regular Medical Doctor, 2013," Government, (June 12, 2014), <http://www.statcan.gc.ca/pub/82-625-x/2014001/article/14013-eng.htm>.

One might argue that in cases of ACP, the dilemma between the various biomedical ethics principles is simply dissolved because a person is able to clearly indicate which set of principles or principle one would rather choose. However, as I have argued above, ACP does not fully capture what a patient would want in not only unanticipated, but also often in anticipated, circumstances.

Let us now explore ACP and the role of deception in ACP through the lens of the bioethics principles. First, one might argue that ACP is superior to deception regarding respect for autonomy. ACP involves clear discussions with a person in advance to ensure that his or her wishes are being respected. However, as described above, respect for autonomy involves accurately representing and respecting the wishes of a person. The concerns raised about ACP show that respect for autonomy may actually be a false sense of respecting autonomy, since ACP often does not adequately capture a person's values and wishes, as it is unreasonable to be able to anticipate what it is actually like to be a patient experiencing a particular situation. When considering using deception, one ought to think about what the person would want given her previous wishes and values – which can be captured in ACP, but has significant limitations. Discussion surrounding deception can involve considering the restoration of autonomy, when possible, and respected any previous wishes that a patient may have expressed. ACP can certainly be a starting point for discussion, but the specific details of potentially using deception and how it would impact autonomy should be considered at the time of the decision, when the details of the case are best known; it is at this point when ACP could be interpreted and further examined with the assistance of the SDM. Hence, regarding autonomy, ACP is not clearly a plausible alternative to the use of deception. These intricate

discussions ought to occur when considering what the patient would actually want given the circumstances and interpretation of ACP.

One could argue, contrary to my claim that deception is something that ought to be determined at the time of the actual decision, that someone who loses mental capacity would be exhibiting false wishes, values and desires at the time the decision needs to be made; following these false values and wishes would certainly not be respecting the authentic or substantial autonomy of the patient. Rather, ACP would be a much more accurate impression of what the patient would actually want during these times.

In response to this objection, I would argue that ACP is useful as being *part* of this decision to have an indication of what the person would have wanted. Nonetheless, I do believe that having a discussion with the SDM(s) and healthcare team in light of the bioethics principles and as well as the current circumstances would illuminate what the patient would actually want given the new circumstances, as values and wishes may change – incapacity is not a good indication of new values and wishes, but relying rigidly on ACP will also fail to capture changed wishes over time and in new circumstances. ACP helps to inform whether a particular patient might have wanted to use deception for care. Nonetheless, the specifics of each case would also inform whether deception is the morally correct course of action, especially given that ACP is often incomplete and requires further discussion in order to fully capture a patient’s wishes given new circumstances and a better understanding of what it is like to be in the current situation. This is not to say that one ought to reject ACP, but rather that it is useful as a starting point, and can in some cases actually be an accurate representation of the patient’s wishes regarding what one ought to do.

The second major bioethics principle is beneficence. Beneficence aims at acting in the patient's clinical best interests to promote flourishing; beneficence aims at encouraging increased capabilities based on a general consensus of well-being. ACP focuses heavily on patient autonomy, and less so on beneficence in this traditional sense. How does each ACP and deception align with beneficence? First, the nature of autonomy is that it might conflict with clinical and general shared best interests. Autonomy represents much more nuanced interests, values and beliefs based on more specific persons and context, including social, ethnic, cultural and religious influences, to name a few, than those more general interests considered in beneficent best interests.

When considering ACP as a source of moral justification or considering deception as a treatment option on its own, how is beneficence involved in each alternative? ACP focuses primarily on the autonomous wishes of a patient and arguably does not allow for a broad discussion of the benefits and harms associated with a particular treatment and its alternatives. One would hope that these discussions would occur at the time of ACP with the appropriate people involved; however, as described above, given the lack of resources and given certain patient populations, it is unlikely that ACP is completed in this manner. The use of deception aims not only to satisfy respect for autonomy, but also beneficence and the other bioethics principles; each of the bioethics principles are considered and applied to the case – I will discuss how one weighs and balances the principles in Chapter Four. Also, I believe that beneficence allows for a richer discussion of alternatives and perspectives that the patient may actually share, rather than focusing too narrowly on simply what the patient would have wanted. Sometimes, introducing ideas of what others might choose, can help to reveal new

alternatives and beliefs that may more accurately represent the patient's wishes, but may have just not been verbalized.

That being said, if ACP could be completed more effectively, for example, if we had more healthcare resources to be able to allow patients to make more informed choices (although I do believe that being in a particular situation provides the best insight, when possible), then clinical best interests would be more useful at the time of participating in ACP; this would at least better inform ACP. Nonetheless, I have described above the difficulties associated with ACP regarding allowing for a change of mind and the specifics apparent at the time of the actual decision whether to treat or not. Hence, the discussion related to the use of deception (perhaps informed by ACP) ought to occur more rigorously at the time of the decision given the patient's specific situation.<sup>59</sup>

The third major bioethics principle is non-maleficence. I have described above in detail many of the concerns associated with ACP, and those associated with deception. When considering non-maleficence, one ought to think about the harms associated with each option and whether the benefits outweigh those harms. One harm associated with ACP includes creating uninformed plans that ultimately do not align with one's values and wishes when one loses mental capacity, while still being relatively binding; this could mean completing ACP without being fully aware of various options, and how those options will actually unfold. Another harm that could result from ACP is being *locked in* to particular choices that can change; for example, as described above, when one actually experiences certain medical procedures or a change in one's health, one's perspective can often change as well, causing a

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59. I am not arguing that Community Treatment Orders ought not be used – in fact, I believe that in those cases where the patient's wishes are known, given an extensive history with the patient, then CTOs are very useful for respecting patient autonomy. Additionally, this is in keeping with reflecting on the other bioethics principles at times of lucidity and also harm reduction approaches.



genuine adjustment of values, beliefs and oftentimes life goals. ACP can be harmful in each of these cases, as one is forced to abide by these wishes, without having the judgment necessary to allow for new information to influence a decision or a genuine change of values.

The use of deception can also have significant harms. I argue that these potential harms inform whether or not one ought to proceed with deception in light of balancing and weighing them with respect for autonomy, beneficence, justice and trust. The harms one can experience with deception are related to, but not exclusive to, trust – deception can damage the important fiduciary relationship between a patient and caregiver. This damage can include refusal for the patient to return to healthcare organizations in future, and noncompliance with future medical treatment.<sup>60</sup> In these situations, enormous sources of medical and emotional support are destroyed. Other harms that can stem from deception include patients believing (in cases where medication/treatment is provided) that they got better on their own and no longer need these kinds of healthcare services – this reveals the importance of disclosing that the patient was given medication surreptitiously once he or she is in a capable state, when possible. I have discussed the negative impact of trust on patient populations when using deception. There can be some positive implications for trust when using deception – these include trust as reliability and trust as maintaining a therapeutic relationship. Other harms will be discussed further in Chapter Three.

At face value, deception appears to have many harms associated with its use, but it is important to keep in mind that these harms are contingent on the particular patient and that patient's experience – hence, supporting my patient-centered position on the use of deception. Choosing to use deception may be morally indefensible for certain patients, but extremely

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60. Although, studies show that once patients receive medication covertly, and it is clearly declared that this occurred, most patients (although upset with deception) are compliant with taking medication in future.

beneficial and useful for others, again, dependent on the specific patient and his/her situation (not exclusive to autonomy).

Justice is also a key factor when comparing both ACP and deception. As described in Chapter One, one important component of justice is providing opportunities for vulnerable populations to be able to live the kind of life where one can make goals and decisions for oneself. To be in this position, one can have mental capacity restored, when possible, or at least restored to a functional state. Justice also includes protecting the interests of those vulnerable populations who are unable to do so for themselves. One of the main reasons for completing ACP is precisely to protect loved ones and their interests in times when they are no longer capable of doing so for themselves. Can ACP reasonably and practically achieve this goal? I have argued above that realistically it cannot, on its own. ACP provides only a piece of the puzzle that is ever expanding and changing when new life experiences occur – hence, ACP is perhaps a good starting point to have further discussions based on a specific situation.

One of the goals of deception is similarly to protect vulnerable populations. Its aim is to restore mental capacity such that vulnerable populations have the kinds of opportunities available to others – fundamental to the notion of justice in bioethics. For patients who cannot have restored mental capacity, justice requires that the interests of those who can no longer do so for themselves be protected. Deception can include protecting these patient populations and their interests, including substantial autonomous values and wishes, as well as beneficent interests. A patient-centered approach to deception promotes justice because, when appropriate, deception aims at providing opportunities to vulnerable populations who would otherwise not have these opportunities, or have these opportunities at a high cost (such as in

the case of physical restraints). It also takes into consideration when deception is indefensible, depending on each unique case and the variables that occur with each case.

I argued in the previous section that there is no clear morally preferable option between ACP and using deception but rather that deception can likely be an inevitable part of ACP, even when ACP is completed well. In addition, the practicality and application of ACP has many concerns and risks and ACP is not extremely reliable on its own. However, ACP can provide some insights into the wishes of an individual, which ought to be discussed and further qualified through conversations with SDMs.

I am not fundamentally against either the use of physical restraints or ACP, but I have argued that they have significant limitations, as does the use of deception in caregiving. Arguing that one or the other is always the best alternative compared to the use of deception is not a feasible position. Instead, the context and each specific situation have moral variables and morally relevant factors that make one position more morally justifiable than another.

### **Absolute Truth-telling**

The final alternative to deception that I will examine in this chapter is absolute truth-telling, which is being fully honest with patients who lack mental capacity regarding taking medication and personal circumstances. One example could involve reminding a patient with advanced Alzheimer's disease that her husband passed away many years ago, when she asks for him. Absolute truth-telling ensures decision-making is systematic and simple, and leaves caregivers with clear guidance. Caregivers also avoid the negative feelings associated with deceiving patients.

Truth-telling is often raised in the context of informed consent and the duty of healthcare providers to present full information to patients when making healthcare decisions. This empowers patients and promotes their autonomy to make decisions for themselves. Truth-telling also promotes trust, as I described earlier. Truth-telling can foster a good therapeutic relationship with caregivers. On the surface, truth-telling appears to be a clear morally defensible alternative to deception. Let us look in depth at truth-telling in relation to the biomedical ethics principles to determine whether it is a morally plausible alternative to deception.<sup>61</sup>

It is important to note that absolute truth-telling may need to be used in conjunction with the other alternatives discussed, including physical restraints. For example, absolute truth-telling may also involve using physical restraints if a patient's behaviour has escalated and cannot be deescalated using other methods. More recently, an adopted approach is to clearly notify patients that they must either take a medication or force will be used to administer the medication.<sup>62</sup> However, this is often in times of crisis as opposed to regular medication routines. This kind of direct coercion is anecdotally quite effective for patients taking their medication. Nonetheless, there are concerns with its perhaps overly paternalistic and coercive nature, especially regarding trust. On the one hand, it is respectful to offer a choice to patients. On the other hand, this choice is not a free one, but is rather a firm and authoritarian approach. As a different example, absolute truth-telling for a patient who asks where her deceased

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61. An analogous case to truth-telling and deception would be that of truth-telling and hope. In some cases, family members request that they not be given pertinent information regarding their diagnoses because hope is something that allows the patient to keep trying and stay positive during challenging times – even though the patient understands that it may not.

62. McWhinney, "Are We on the Brink of a Major Transformation of Clinical Method?," 2.

husband is, may not involve other alternatives. Hence, absolute truth-telling may not be distinct from other alternatives, but deserves its own analysis in light of cases such as the latter.

One might argue that truth-telling respects autonomy. If patients are fully aware of the facts regarding their medication or whether their loved one is alive or has died, then they are able to make decisions for themselves by exercising their autonomy. As described earlier, however, the group of patients that I am interested in are those who lack substantial autonomy. It may also be argued that although this patient population lacks substantial autonomy, such as the autonomy to make treatment or placement decisions, they may be able to understand and appreciate other kinds of information, for example that their loved one died.

Let me first examine deception and treatment cases, and then explore truth-telling in the kinds of cases where a patient has specific personal circumstances. In cases of treatment, does truth-telling enhance and/or respect autonomy more so than deception? In cases where a patient is able to understand and appreciate the full context of taking ones' medication: the risks, benefits, consequences of not taking the medication and so forth, the patient should be provided the appropriate information to make a decision; this respects the patient's autonomy and allows the patient to provide an informed consent or refusal.

However, the kinds of cases that I discuss (those where a patient suffers from psychosis or the nature of his/her illness, for example), patient autonomy is lacking to a robust degree, and truth-telling can actually further impede restoration of autonomy. For example, if a patient is experiencing a psychotic episode, telling the patient the truth about medication and attempting to convince the patient to take the medication may or may not be successful. This will depend heavily on the relationship between the caregiver and the patient, including trust, as well as the kind of psychosis that the patient is experiencing. Sometimes the patient might

be willing to take the medication, and other times not. Again, the use of deception is dependent on numerous factors, including the substantive autonomous wishes of the patient when capable and the relationship between caregiver and patient. Deception, used in those cases where the patient would likely want autonomy restored, might be more supportive and conducive towards the enhancement and restoration of autonomy than truth-telling, if rational persuasion has been unsuccessful in the past or is unlikely.

Let us now consider the kinds of cases where a patient suffers from advanced Alzheimer's disease and is inquiring about a personal matter. For example, consider a patient asking after her husband who has deceased; does truth-telling respect autonomy? The patient may not be able to understand and appreciate complex treatment and placement decisions, but she may be fully capable of understanding what it means that her partner has passed away. If the patient does understand this information, then it would be worth discussing with her whether she would want to be informed the her husband has passed away when she asks in future, and in light of the effect it has on her mood, behaviours and quality of life more broadly. If this is not possible during moments of lucidity, then one ought to have a discussion with the patient's SDM(s). Trying to determine the patient's autonomous wishes would provide much insight into what she would want. Having these kinds of conversations would also permit caregivers to plan what one should do in future, such that this conversation need not occur every time the patient inquires.

In those cases where a patient is incapable of understanding this information, it would again be important to determine the patient's previous autonomous wishes. If the wishes are not clearly known, exploring the benefits and risks associated with disclosing are important to determine what would be in the patient's best interests. Hence, in some circumstances

deception may respect autonomy more so than absolute truth-telling. Nonetheless, truth-telling would be ideal, if the situation arises such that it is possible to do so and to have the kind of desired effects.

The second major biomedical ethics principle is beneficence – how do both truth-telling and deception compare when considering the best interests of patients and doing good for patients? As I have described in the earlier paragraphs of this section, acting in the best interests of the patient will depend heavily on the benefits and risks of the use of deception or of truth-telling for each specific patient. Some of the benefits of truth-telling include fostering important trust relations with one's patient and being consistent in one's interactions, to encourage and enforce reliability of treatment. However, I have described a patient population that may already have a significant distrust toward healthcare providers and the healthcare system, due to their illness. In these kinds of cases, acting in the patient's best interests might include trying to restore autonomy, as we value autonomy, making decisions for ourselves and trying to improve trust relations through truth-telling and/or reliability.

In cases where a patient suffers from advanced Alzheimer's disease, acting in the patient's best interests could mean deceiving the patient such that he/she will not experience the suffering associate with learning and re-learning the news that their loved one has passed away every time that he/she asks.<sup>63</sup> Since the restoration of autonomy is not a viable option in these cases, reducing suffering and doing no further harm to the patient would be acting in the patient's best interests, unless one has reason to act otherwise.

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63. Sean A. Spence et al., "A Cognitive Neurobiological Account of Deception: Evidence from Functional Neuroimaging.," *Philosophical Transactions of the Royal Society B: Biological Sciences* 359, no. 1451 (November 29, 2004): 1755–62.

Non-maleficence requires caregivers to not place any undue harm on a patient, in relation to the potential benefits of an action. Hence, one weighs the risks and the benefits, and proceeds with the option in which the benefits outweigh the risks, more so than other alternatives. Again, I advocate a case-by-case analysis of each unique patient, as each patient will experience deception/truth-telling differently based on her past experiences, values, wishes and desires. In the case of deception and covert medication for incapable patients, one must examine the risks associated with covert medication. I have listed several of these risks previously, including medication interference, fear associated with side-effects when the patient is unaware why they are occurring, and loss of trust if the patient discovers medication is being hidden in her food and/or drink. These are significant concerns, and ought not be taken lightly.

The benefits of taking the medication, however, may outweigh these concerns depending on the pertinence of these concerns and the results from taking the medication. Consider an incapable patient who suffers from psychosis who lives on the street and frequently uses recreational street drugs; also consider an incapable patient who is reclusive and stays at home all of the time and does not take any other drug or medication – one might infer that the risks associated with the drug interactions of the first patient are significantly higher than those of the second patient. Hence, one needs to explore carefully whether deception, truth-telling or another alternative would be most appropriate for each particular case. The decision framework I develop in Chapter Four will help frame this decision process.

Similarly, consider cases of incapable patients who suffer from advanced Alzheimer's disease. Consider two different patients. Upon hearing the news that her husband died, the first patient becomes extremely depressed, reclusive and spends all her time in her room crying and



not participating in the daily activities that normally bring her much comfort and happiness. The second patient generally cries for a short period of time upon hearing the news, and then she is able to continue her day participating in activities that she enjoys and finding comfort in spending time with her friends in the care facility. The first patient could benefit significantly from being deceived about her husband, whereas the second case would not significantly impact the patient. One must also consider the issue of trust if, for example, a family member/friend told her that her husband did die, whilst the staff lied. This could create significant risks that do not seemingly outweigh the benefits. There are of course other factors to consider, such as the authentic autonomous wishes and values of the patient prior to losing capacity; I will discuss these in more detail in the next chapter.

I have briefly discussed the notion of trust and how it is impacted by deception or truth-telling; let me expand on this further. Truth-telling fosters trust not only with those patients who have capacity, but also can do so with patients who lack capacity. Sometimes even a patient who is floridly psychotic can process information, but perhaps not in a meaningful way. For example, the patient in this condition may be able to point to inconsistencies in what the caregiver is saying, yet not have an appreciation for the consequences of not taking medication. Hence, truth-telling can enhance some forms of trust, even though it may be relatively small due to the patient's condition. One must further consider the benefits and harms associated with the act of truth-telling in relation to each patient.

Trust, as I have described above, can also take the form of reliability. Reliability often means consistency in what one says and does (with which truth-telling is conducive). In the context of healthcare, reliability also includes healthcare providers acting upon the expectations of patients and society. For example, when a patient suffering from psychosis is

threatening others, the healthcare system ensures that patient is held under observation and accordingly treated appropriately with the SDM's informed consent. This ensures that not only the general community is safe, but also that the vulnerable patient is also protected and safe. Reliability often accords with truth-telling, but one can imagine the kinds of cases where being deceptive enhances this form of trust; for example, covert medication ensures that patients who require medication (and have consent via a SDM) have reliable access to treatment and medication. Hence, deception can enhance trust as a form of reliability regarding expectations of treatment when in a dire condition.

Lastly, issues of justice arise in these cases. The patient populations that I explore are particularly vulnerable, those who lack capacity and require some additional assistance. The groups that I focus on are those with mental illness and dementia. These populations are often stigmatized and not considered as seriously as the more prominent and well-funded illnesses, such as cancer and diabetes. How do truth-telling and deception compare regarding issues of justice and healthcare?

One might argue that truth-telling is one way to treat vulnerable populations with respect and to not marginalize these groups who already face much stigma and discrimination. Truth-telling involves being completely honest and allows full access to information – vulnerable populations are often denied this kind of treatment.<sup>64</sup> Deception contrarily denies access to information and further creates barriers for vulnerable populations, feeding into the injustices that they already face.

In cases where patients have capacity, the disclosure of the use of medication and its associated risks, benefits and so forth, is fundamental. Even though an incapable patient may

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64. Margaret S. Cashen, Patricia Dykes, and Ben Gerber, "eHealth Technology and Internet Resources: Barriers for Vulnerable Populations," *Journal of Cardiovascular Nursing* 19, no. 2 (June 2004): 209–14.

not be able to understand and/or appreciate the discussion surrounding medication, the involvement of the patient can often provide insights into what ought to be done, as well as can foster trusting relationships with the patient, SDM(s) and healthcare providers. For example, if an incapable patient is refusing medication, involvement for decision-making with the patient could reveal the patient's concerns with side-effects, which may lead to a change in the medication that the patient is on or whether the patient should be on any medication at all.

I argue that there are, however, other cases when weighing and balancing risks and benefits associated with taking the medication could indicate that taking the medication is best for the patient, if even the patient refuses the medication. In these cases, covert medication might be appropriate and morally justified through protecting and advocating for vulnerable patients who cannot understand and/or appreciate risks and consequences; this involves not telling the truth at the outset of providing medication, but rather deceptively hiding the medication to restore autonomy or provide other significant benefits.

Justice through providing vulnerable and often marginalized populations opportunities that they would otherwise be unable to receive can mean being deceptive in specific situations. As described above, I do believe that truth-telling in most cases is the appropriate course of action. However, if it is believed that by being deceptive there could be significant benefits in relation to risks through a thorough consideration (which will be described further in Chapter Four), then deception could be the morally justified course of action.

It may be the case that a patient would value absolute truth-telling above the other bioethics principles, including autonomy, non-maleficence, beneficence, justice and trust. However, I think that these cases would likely be rare. In fact, studies such as the Chennai study reveal that in retrospect, most patients agreed that the use of deception was justified

under the circumstances when it was used.<sup>65</sup> A further consideration is whether any of the other alternatives would be used given that truth-telling sometimes would require being paired with physical restraints, for example. In these kinds of cases, one ought to explore the bioethics principles and associated harms/benefits for both truth-telling and physical restraints in comparison with the use of deception.

In this section, I explored whether absolute truth-telling or deception is the morally appropriate response for the kind of patient populations I am interested in examining. I have argued, as I did with the use of physical restraints, that the context of the case is extremely important; there are cases, perhaps the majority of cases, where the principles of biomedical ethics will favour and morally justify the use of truth-telling over deception. Nonetheless, one ought to consider that there may be other cases where deception may be the morally defensible alternative.

### **Conclusions**

Despite there being alternatives to deception that are often cited, we may have more reasons to use deception in particular cases, and good moral justification for doing so. These reasons are grounded in beneficence, non-maleficence, respect for autonomy, justice and trust. The conflict that caregivers face cannot be resolved simply by using alternatives, but requires a detailed analysis and a moral defense of which option is more morally justifiable given the particular circumstances of each individual patient.

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65. It is also important to note that much of the literature on truth-telling for patient's who suffer from advanced Alzheimer's disease focuses on the disclosure of the diagnosis of Alzheimer's disease and dementia, and does not discuss disclosing other information such as when a patient requests information about a loved one who has died.

I have argued that each of physical restraints, ACP and absolute truth-telling are not definitive alternatives to the use of deception. Instead, there may be circumstances when one would be the more morally appropriate action over another; for example, when a patient is extremely aggressive and de-escalation strategies have not yet worked, and the use of physical restraints could be morally justified over the other options. I have also argued in this chapter that ACP ought to involve deception as a possibility for treatment in future – they are not mutually exclusive; however, there are also significant concerns with ACP and it ought to help guide difficult healthcare decisions, but not exclusively determine what providers and caregivers ought to do in particular situations. In addition, I argued that in cases where patients lack mental capacity, it is not evident that truth-telling is always the morally appropriate action. Although I do believe the truth-telling is morally appropriate in most cases, there are some cases where telling the truth (at least at the onset when considering and providing covert medication) could result in much more harm and risk than good compared to the benefit-risk ratio of using deception.

When considering which alternative is the most morally defensible position, it is necessary to consider the patient’s personal and unique experiences and history. For example: What has been previously attempted? What kinds of responses have been effective or not effective and why? Are there any underlying reasons why the patient has been hesitant or resistant to take medication? The Sheffield Care Homes in the United Kingdom states that it is necessary to consider: “...reasons why the service user may not be taking the prescribed medication.”<sup>66</sup> They list the following factors that might contribute to patients being resistant to taking medication:

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66. Sheffield Care Homes (NHS Foundation Trust), “Good Practice Guidance on Covert Administration of Medication,” 2013.

1. they do not understand what to do when presented with a pill or a spoonful of syrup;
2. they find the medication unpalatable;
3. they have difficulty swallowing the formulation;
4. they lack understanding of what the medication is for;
5. they do not understand in broad terms the consequences of refusal.<sup>67</sup>

It is important to build relationships with patients and to foster good communication. This often requires time and patience. Nonetheless, the ultimate aim is to build trust with patients and to have a greater understanding of the person-focused or patient-centered needs of each patient. Additionally, consider other needs that can be addressed. For example does the patient have existential suffering regarding purpose at end-of-life and how can the caregivers best attend to these needs? Perhaps deception and these other alternatives can be avoided altogether. I will discuss the decision procedure in further in Chapter Four.

To conclude, when considering the circumstances for each unique case, deception might be a plausible alternative, and can be the most morally defensible option for caregivers in certain situations. These situations occur when the benefits of using deception (based on specifying the principles to the specific case) outweigh the risks of its use, and provides greater overall ratio of benefits to risks than other alternatives. I will discuss how one judges and reflects on balancing and weighing risks and benefits in the fourth chapter, highlighting the importance of a patient-centered approach. In the following chapter I will elaborate on the reasons provided for and against the use of deception – I previously discussed those of the biomedical ethics principles as foundational ethical considerations, but will expand on other effects, consequences and important factors.

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67. Ibid.

## **Chapter 3**

### **Further Factors to Consider for Deception**

In the two preceding chapters, I discussed the traditional major biomedical ethics principles and how they each apply to the kinds of deception cases that I explore; I discussed enhancing and respecting autonomy, justice, non-maleficence and beneficence, as well as fostering trust.

What are other important considerations that should be weighed and balanced when determining what caregivers ought to do? In this chapter, I will further examine philosophical factors to consider in favour of and against deception for these cases; many of which build on the biomedical ethics principles. In Chapter Four, I will discuss how caregivers ought to weigh and balance the factors.

In this chapter, I will first discuss the legal and professional constraints on healthcare providers (as a subset of caregivers). I will then explore further factors provided in favour and against the use of deception expanding on those provided in Chapter One, under the broad categories of deontology, consequentialism and virtue ethics. I believe that there is some overlap between these categories and I will discuss various theoretical perspectives for each factor provided. Additionally, I believe that these factors are not distinct from the categories argued for by Beauchamp and Childress, but need to be addressed beyond their traditional principlist approach. I will divide each section into two parts: (1) factors to be weighed in Chapter Four; and (2) considerations that I will be setting aside. I will argue why each consideration fits into each category. This chapter will help to organize and defend why certain factors ought to be weighed and balanced, and in Chapter Four I will explain how one ought to do so.

## **Legal and Professional Constraints**

In this next section, I will focus on several important duties of professionals towards their patients/clients as well as to society at large. This section focuses on several deontological, or duty-based, constraints on deciding whether to use deception. Patients in Canada have certain rights, and caregivers have duties, including professional, legal and ethical duties, to uphold these corresponding rights.

### *Informed Consent*

Under the Health Care Consent Act (1996), no treatment will be administered without informed consent provided. A capable patient usually gives informed consent for her healthcare decisions, and capacity is always presumed, unless proven otherwise. If a patient is found to be incapable for a particular treatment or placement decision, then a substitute decision-maker (SDM) is responsible for making decisions on behalf of the patient. The information provided in the consent discussion is as follows: “(i) the nature of the treatment, (ii) the expected benefits of the treatment, (iii) the material risks of the treatment, (iv) the material side effects of the treatment, (v) alternative courses of action, and (vi) the likely consequences of not having the treatment.”<sup>1</sup> Patients have a right to know all of this information and decide whether they would want to proceed with a particular treatment decision or not.

It is often encouraged that incapable patients participate in the decision-making process, as they can add valuable insight into what they would want, despite not being able to

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1. *Health Care Consent Act.*



be the ultimate decision-maker.<sup>2</sup> It may also be the case that incapable patients are able to describe the treatment goals they wish, depending on their condition. They may however not be able to understand or appreciate how to achieve this goal and find it challenging to consent to a plan of care given their condition; this is when a SDM would assist with the decision. Nonetheless, although it is highly encouraged that caregivers and SDMs involve incapable patients in the decision-making process, this is not a requirement.

For cases of deception, it is essential to receive consent from either the patient (when capable, during moments of lucidity) or the SDM(s) for incapable patients. As described above, in Ontario, Canada this is a legal and professional duty. It is also an ethical duty that healthcare providers respect the autonomy of their patients – their values, wishes and beliefs. Deception in the kinds of cases that I describe aims at doing precisely this – respecting (and restoring when possible) the autonomy of each patient. In the process of deciding whether or not to use deception, it is important and absolutely necessary to involve the appropriate decision-maker(s), and to obtain an informed consent from the decision-maker(s). Hence, deception does not violate one’s legal, professional and ethical obligation of informed consent if it is obtained from the appropriate decision-maker.

#### *Right to Choose / Right to Treatment*

Patients have the right to make decisions that are seemingly in conflict with what healthcare providers may determine and feel is in their best medical interests. Patients can refuse treatment (for example one that might save their lives) if they are capable. Capability means that they have the ability to understand and to appreciate all of the information provided

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2. Johannes Hamann et al., “Shared Decision Making for In-Patients with Schizophrenia,” *Acta Psychiatrica Scandinavica* 114, no. 4 (2006): 265–273.

through the informed consent process, and have had a thorough opportunity to ask questions and discuss the decision with those appropriate. The American College of Obstetricians and Gynecologists' Committee on Professional Liability write:

In spite of a physician's medical advice or recommendation, a patient who is informed of the material risks and benefits of a particular treatment, test, or procedure, may elect to forgo all or some of these or may decline a procedure or test that might be recommended or become necessary during treatment.<sup>3</sup>

An informed refusal is based on respecting the patient's values, wishes and beliefs. This choice can of course cause much distress among staff and physicians, but is nonetheless a patient's right.<sup>4</sup>

Patients may choose to refuse treatments for various reasons, including religious and cultural values and personal preferences. Consider a patient who is a Jehovah's Witness and chooses to not have a leg amputation (which would save her life) because it would require a blood transfusion (often prohibited in her religion), assuming she has full capacity to make this decision. Another example of an informed refusal could be due to the preference to not experience particular symptoms from taking medication. An example of this kind of refusal is reported for patients who have bipolar disorder and would rather experience the creativity during the manic or high stages of the illness along with the low experiences, than to be on medication.<sup>5</sup> Additionally, some anti-psychotic medication (especially those used in the past) have had the side effect of random body spasms and compulsions; patients may chose to not

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3. American College of Obstetricians and Gynecologists, "ACOG Committee Opinion: Informed Refusal," *International Journal of Gynecology and Obstetrics* 74, no. 1 (July 2001): 68.

4. *Constitution Act: Part 1. Canadian Charter of Rights and Freedoms*, 1982, <http://laws-lois.justice.gc.ca/eng/const/page-15.html>.

5. Francesc Colom et al., "Identifying and Improving Non-Adherence in Bipolar Disorders," *Bipolar Disorders* 7, no. s5 (2005): 24-31.

experience these side effects and rather experience the symptoms of the illness.<sup>6</sup> Similarly, patients who have depression will often not take medications due to the side effects of gaining significant weight. Hence, there are a wide variety of reasons why someone may rationally choose, against medical advice, to refuse a treatment.

If a healthcare provider were to force a patient to take treatment contrary to her capable values and wishes, this would constitute assault and battery under Canadian law. *Schloendorff v. Society of New York Hospital*, 1914, was the first American case where a judge ruled in the favour of a patient against physicians who had acted against the patient's prior expressed capable wishes. Green and MacKenzie write: "...the Schloendorff case is rooted in the principle of autonomy: 'every human being of adult years and sound mind shall have the right to determine what shall be done with his own body...'"<sup>7</sup> The latter quotation is the infamous words of Justice Benjamin Cardozo, the judge responsible for the ruling.

The Canadian Medical Protective Agency further writes:

A physician may be liable in assault and battery when no consent was given at all or when the treatment went beyond or deviated significantly from that for which the consent was given. Allegations of assault and battery might also be made if consent to treatment was obtained through serious or fraudulent misrepresentation in what was explained to the patient.<sup>8</sup>

In this quotation one can see why deception may have very serious consequences if a physician or healthcare provider misrepresents information to a patient against her capable prior expressed wishes and values.

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6. National Institute of Mental Health, "Mental Health Medications" (U.S. Department of Health and Human Services, 2015), <http://www.nimh.nih.gov/health/publications/mental-health-medications/index.shtml>.

7. Douglas S.T. Green and C. Ronald MacKenzie, "Nuances of Informed Consent: The Paradigm of Regional Anesthesia," *HSS Journal* 3, no. 1 (February 2007): 115–118.

8. Kenneth G. Evans and Gowling Lafleur Henderson, *Consent: A Guide for Canadian Physicians*, 4th ed. (The Canadian Medical Protective Agency, 2006), [http://www.cmpa-acpm.ca/cmpapd04/docs/resource\\_files/ml\\_guides/consent\\_guide/pdf/com\\_consent-e.pdf](http://www.cmpa-acpm.ca/cmpapd04/docs/resource_files/ml_guides/consent_guide/pdf/com_consent-e.pdf).

On the flip side, a physician may not provide a treatment to a patient that she believes is medically inappropriate or would cause excessive risks in relation to the benefits. There is much debate at the moment regarding the difference between withdrawing treatment and withholding treatment given a physician's determination of what is medically *futile*. The HCCA (1996) requires consent to withdraw any treatment, whereas if a physician decides not to offer a treatment (withhold a treatment) patients and SDMs can request a second opinion, but not require that a physician provide the treatment. Hence, if a treatment were already started, the physician would require consent to remove it.<sup>9</sup> The discussion of medical futility is unfortunately beyond the scope of my thesis. The point that I am raising in this context is that patients have a right to refuse treatment, but also have limitations on what they can request from physicians and healthcare providers, if a treatment has not already commenced. Capable patients who are fully informed have a right to refuse to take certain medications and to refuse particular treatments – this is their legal right, and healthcare professionals have a duty to respect that decision.

Patients also have the reverse right to basic healthcare in Canada.<sup>10</sup> Canadian citizens are covered by provincial health insurance for many basic treatments and medications and, when sick, physicians have a duty to provide reasonable basic healthcare options to their patients.<sup>11</sup> Not providing treatment and not seeking appropriate healthcare alternatives for their

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9. See for example *Cuthbertson v. Rasouli*, 3 SCR 341 (SCC 2013)..

10. By “basic” healthcare, I refer to the Canada Health Act, which defines basic healthcare as those treatments that are medically necessary, such as many medications, treatments and surgeries. Some, however, are not considered necessary, and will be paid for by private insurance and/or out of pocket, such as dentistry and optometry (*Canada Health Act*, RSC 1985, C. C-6, 1985, <http://laws-lois.justice.gc.ca/eng/acts/C-6/page-1.html>).

11. *Ibid.*

patients constitutes medical negligence. The Canadian Medical Protective Agency defines medical negligence based on Chief Justice Mathers' definition from his ruling:

The definition I gave you was that the defendant would not be liable for negligence unless he did something that an ordinary, reasonable practitioner, in his branch of the profession, would not have done, or that he omitted to do something which an ordinary practitioner in his branch of the profession would have done.<sup>12</sup>

Hence, negligence relies heavily on standard practice – what other physicians with similar qualifications would do in the same situation. Patients ought not be denied basic healthcare, unless the treatment and/or medications do not adhere to standard practice or appropriate care. Weijer et al. remark: “‘Appropriate care’ is most productively understood as treatment that falls within the bounds of standard medical practice, that is, medical interventions used by at least a ‘respectable minority’ of expert practitioners.”<sup>13</sup> These concepts rely on what professional physicians would consider as regular care. Of course, certain exceptions can be made based on cultural and religious grounds, often only if there is not significant burden in relation to benefit to the patient and other stakeholders. Boundaries between appropriate and inappropriate care can become blurred surrounding cases where there is dispute when defining quality of life and best interests of the patient.<sup>14</sup> Medical negligence occurs when substandard care is provided. In this thesis, I argue that deception, under the limitations that I provide, should be part of standard of care for certain cases.

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12. William D.S. Thomas, *A Physician's Foresight, a Profession's Pride: A History of the Canadian Medical Protective Association* (Ottawa, ON: Canadian Medical Protective Agency, 2001).

13. Charles Weijer et al., “Bioethics for Clinicians: 16. Dealing with Demands for Inappropriate Treatment,” *Canadian Medical Association Journal* 159, no. 7 (October 6, 1998): 818.

14. *Ibid.*, 820.

Another similar concept is therapeutic abandonment. This occurs when there is an unreasonable termination of the physician-patient relationship (or healthcare provider-patient relationship). The Rheumatology Network defines abandonment as the following:

...the termination of a professional relationship between physician and patient at an unreasonable time and without giving the patient the chance to find an equally qualified replacement. There must be some harm from the abandonment. The plaintiff must prove that the physician ended the relationship at a critical stage of the patient's treatment without good reason or sufficient notice to allow the patient to find another physician, and the patient was injured as a result. Usually, expert evidence is required to establish whether termination happened at a critical stage of treatment.<sup>15</sup>

Clinical judgment is certainly important in determining whether a patient is at risk of suffering a significant injury if the healthcare provider were to end the therapeutic relationship. Therapeutic abandonment is generally considered in terms of the entire healthcare provider-patient relationship, whereas negligence is applied to a specific act. If the use of deception were ethically defensible for a particular case and is standard practice, then not incorporating it as part of the plan of care could constitute negligence. If a healthcare provider felt that it were not ethically defensible to use deception in the treatment plan of the patient, then one ought to have another alternative available for the patient's treatment.

#### *Right to Personal Health Information (PHIPA)*

If a patient, whom the healthcare team and/or caregiver believe would benefit significantly from the use of deception in healthcare, asks whether they are receiving a particular medication or treatment, do healthcare providers have a duty to disclose this information? When ought they, and when should they not?

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15. Martin Merritt, "Ethics on Ending the Patient-Physician Relationship | Rheumatology Network," UBM Medica, LLC, *Rheumatology Network*, (October 27, 2013), <http://www.rheumatologynetwork.com/blog/ethics-ending-patient-physician-relationship>.

Under the *Personal Health Information Protection Act* of Ontario of 2004 (PHIPA), every patient has a right to health information about himself or herself. This information includes, but is not limited to, “the physical and mental health of the individual,” “identification of a person as a provider of health care to the individual” and so forth.<sup>16</sup> The act describes healthcare providers and organizations as “health information custodians” charged with taking care of this information on behalf of patients; this includes only disclosing information to those required by law to do so, and providing information when requested by patients.<sup>17</sup> The main purpose of this act is to protect patient information, such that it is not accessible to those outside of the circle of care, the patient and those required for legal purposes. There is also an *Information and Privacy Commissioner*, to whom someone may complain if they feel their right to information has been denied.

An important clause in PHIPA is under the “Individual’s Right of Access” section, which describes when information may not be disclosed:

52. (1) Subject to this Part, an individual has a right of access to a record of personal health information about the individual that is in the custody or under the control of a health information custodian unless, ...

(e) granting the access could reasonably be expected to,

(i) result in a risk of serious harm to the treatment or recovery of the individual or a risk of serious bodily harm to the individual or another person,

(ii) lead to the identification of a person who was required by law to provide information in the record to the custodian, or

(iii) lead to the identification of a person who provided information in the record to the custodian explicitly or implicitly in confidence if the custodian

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16. *Personal Health Information Protection Act*, SO 2004, C. 3, Sched. A; 2010, C. 11, S. 128, 2004, [http://www.e-laws.gov.on.ca/html/statutes/english/elaws\\_statutes\\_04p03\\_e.htm](http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_04p03_e.htm).

17. Ibid.

considers it appropriate in the circumstances that the identity of the person be kept confidential; or...<sup>18</sup>

The first part of this section discusses when information would be withheld from a patient when there are legal requirements to do so (e.g. a court order prohibits the information being disclosed, or a proceeding has not yet concluded regarding the information, etc.). In this quotation, it reveals that sometimes information ought to be withheld from an individual if there is a serious risk of harm regarding treatment or recovery of the individual him- or her-self and/or to others.

In the case of deception and covert medication, one ought to assess whether there is serious risk to the patient and/or others by disclosing this information. If a patient is having a severe psychotic episode and will wander off in the freezing winter weather, then there would likely be a serious risk to the patient. Additionally, if a patient has significantly increased aggression and poses a risk of harming others and herself then the information should not be disclosed, unless not doing so would be of greater harm. For example, if it were likely that the patient would discover that she has medication hidden in her food/drink she would likely become even more aggressive.

On the other hand, for cases of severe dementia, a patient would likely not question whether it were true, as the deterioration of cognitive abilities often make more complex thoughts and connections between thoughts less probable. Nonetheless, if a patient were to ask and question either covert medication or the truth of statements about events that would cause her much distress, the same principle would apply as above – does the disclosure have the potential to cause serious harm for the treatment and/or recovery of the patient? Of course the evaluation or judgment of harm will depend heavily on one's definition of harm and how

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18. Ibid.



serious it is perceived to be. From one point of view, not taking medication to prevent blood clot formation is a serious risk of harm; from another point of view, perhaps at a particular stage in one's life and given one's condition, this may not be considered as serious. It would be reasonable to consider what the standard of care is – what would other physicians and healthcare providers define as serious harm in a case – and this ought to be considered in light of the patient's wishes and values as well.

Along a similar line of thought, therapeutic privilege is a highly controversial topic in healthcare. Fried and Perlis describe therapeutic privilege as follows:

Therapeutic privilege is the concept that a physician may sometimes deceive or lie to a patient for the patient's own good. One example could include out-right lying about a poor prognosis in an attempt to minimize a patient's associated psychological stress. More subtle examples could include providing limited or incomplete information in order to steer a patient toward a preferred treatment. Therapeutic privilege may attempt to "preserve the patient's hope, and psychological and moral integrity, as well as his self-image and dignity."<sup>19</sup>

Therapeutic privilege is the idea that it is appropriate for healthcare providers to withhold information from patients because it is likely to cause significant distress to patients. This concept is typically used for patients who have mental capacity to make decisions for themselves and is not often applied to patients who lack mental capacity.

This concept uses a paternalistic method for determining whether a patient ought to receive information about her treatment. The healthcare provider, as gatekeeper instead of steward, has clinical and professional judgment to determine if the information would be harmful to the patient. For example, consider a patient who expresses suicidal ideations from chronic depression – this patient is being treated in a healthcare facility and, tragically, her parents are killed in a car accident during her treatment at the facility. It may be appropriate,

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19. Richard G. Fried and Clifford Perlis, "Therapeutic Privilege: If, When, and How to Lie to Patients," in *Dermatoethics*, ed. Lionel Bercovitch and Clifford Perlis (Springer London, 2012), 33.

when possible, to delay providing that information to the patient if the healthcare provider genuinely believed that the information would increase her severe risk of suicide, and it may not be necessary (e.g. for specific decisions) to disclose the information. When the patient is in a safer mental space, it would be appropriate to disclose this information in a sensitive manner.<sup>20</sup>

### *Truth-telling*

An invaluable duty of healthcare providers is to tell the truth. I have already discussed in great deal the moral importance of truth-telling in both Chapter One and Chapter Two. I will now discuss truth-telling in the context of professional duties.

Many different professional colleges and organizations across Canada have practice standards that discuss the importance and requirement of truthfulness. The College of Nurses of Ontario (CNO) includes *truthfulness* as one of their practice standards. The CNO remarks: “Health care professionals now believe that clients have the right to and will benefit from full disclosure. Honesty builds trust, which is essential to the therapeutic relationship between nurses and clients.”<sup>21</sup> The CNO further remarks how there are behavioural directives to assist nurses with deciding how much information is provided and advocating for a patient’s right to know this personal information.<sup>22</sup> One can immediately see a stark opposition between deceptive practices and truthfulness, the latter being a clear practice standard for nurses.

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20. Franklin G. Miller and Luana Colloca, “The Placebo Phenomenon and Medical Ethics: Rethinking the Relationship Between Informed Consent and Risk–Benefit Assessment,” *Journal of Theoretical Medicine and Bioethics* 32, no. 4 (August 2011): 229–233. Along a similar vein, the nocebo effect is a phenomenon that has only recently been explored. This phenomenon extends beyond the scope of this thesis, but aims to highlight how patients can unintentionally develop side effects and/or symptoms explained to them by their healthcare provider, that they would not have developed had they been unaware of them.

21. College of Nurses of Ontario, “Practice Standard: Ethics,” 2009, 17, [http://www.cno.org/Global/docs/prac/41034\\_Ethics.pdf](http://www.cno.org/Global/docs/prac/41034_Ethics.pdf).

22. *Ibid.*, 18.

A major issue in healthcare more broadly is that guidelines often pertain to and are relevant only to those patients who have decision-making capacity, and often neglect patient populations who lack mental capacity. These guidelines focus on those patient populations who can both understand and appreciate their treatment and other decisions. For those patients who cannot understand and/or appreciate, discussing the truth *may, in particular cases*, cause increased harm and not be the authentic wishes of the patient. As described in the introduction, however, there are some professional groups in Canada who strongly discourage deception, without comprehensive moral discussions or justifications for this position.

The Registered Psychiatric Nurses of Canada Code of Ethics does not state anything specific about deception or covert medication, but does indicate that a nurse in this capacity ought to conduct oneself in an honest manner.<sup>23</sup> Standards and guidelines, as with general principles, can come into conflict, such as with the principle do no harm; in these cases, one ought to weigh and balance what one should do. These standards are essentially *prima facie* duties, especially when one experiences conflicting principles.

### **Further Ethical Factors in Favour and Against Deception**

#### *Deontological Factors*

I will now discuss and address some traditional deontological concerns regarding deception. I will not provide an exhaustive consideration of all types of deontological approaches, but will focus on certain deontological ideas that are framed in bioethics, such as the concept of dignity. I will present a thorough discussion of deontological concepts as related to deception in caregiving regarding concerns for human dignity, the intrinsic value of truth and

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23. Registered Psychiatric Nurses of Canada, "Code of Ethics & Standards of Psychiatric Nursing Practice," March 2010, [http://www.crpnb.ca/wp-content/uploads/2011/02/2010\\_Code\\_Standards.pdf](http://www.crpnb.ca/wp-content/uploads/2011/02/2010_Code_Standards.pdf).

universality. In this section and the remaining sections, I will divide each into two parts: (1) factors that will be weighed in Chapter Four; and (2) considerations that I will be setting aside. As mentioned above, I will argue why each consideration fits into each category.

## **Factors to be Weighed**

### *Concerns for Human Dignity*

Human dignity can be a vague expression that many will advance as a factor either in favour of or against deception in caregiving. In this section, I will discuss various definitions of dignity, its merits and why we ought to include dignity in deciding what one ought to do.

Some, such as Ruth Macklin, however, argue that the concept of human dignity is useless; she argues that it simply gets used without significant content.<sup>24</sup> Dignity is a *catchword* that people use to defend all kinds of positions, some of which are opposing. Is dignity such a useless concept, or does it provide something unique and special as opposed to merely representing other bioethics-related concepts, such as respect for autonomy, respect for persons or some other fundamental right that we each have?

Others argue that dignity is unique.<sup>25</sup> In Killmister's article, she describes dignity as being able to abide by one's personal standards. For example, consider a patient who has strong religious convictions, including having one's body fully covered, except for her face and hands. The patient has ALS (amyotrophic lateral sclerosis) and, as a result, she is paralyzed from her neck and below. During a hospital stay she is bathed, and her legs are left partially exposed. This would be a case where her dignity has been negatively affected.

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24. See, for example, Ruth Macklin, "Dignity Is a Useless Concept: It Means No More than Respect for Persons or Their Autonomy," *BMJ* 327, no. 7429 (December 2003): 1419–1420.

25. See, for example, Suzy Killmister, "Dignity: Not Such a Useless Concept," *Journal of Medical Ethics* 36, no. 3 (March 2010): 160–64.

Killmister also associates a loss of dignity with humiliation and shame; however, one can experience a loss of dignity and have different associated feelings, such as anger or hurt, as opposed to shame and humiliation.

Dignity as an inability to abide by one's personal standards is different from respect for persons or autonomy. The concept does not mean respecting the wishes of someone in virtue of being a person, but rather reflects the self-ascribed standards that the person holds. Killmister makes the distinction between autonomy (as self-governance) and dignity (as adhering to one's standards).<sup>26</sup> However, having control over the decisions that impact one's body and life (the standards one lives according to), very much involves autonomy; respecting autonomy is not just the degree of control, but rather naming the standards and having them respected by others.

A feeling of *worth*, associated with having personal standards, is important for dignity.<sup>27</sup> When one's ability to live up to one's standards has been impaired (whether that is caused by others, an illness, oneself, etc.), one often has a feeling of loss of worth or self-value. When one experiences vulnerability, one is more prone to a loss of dignity. Hence, here we can see the distinction between dignity and autonomy – when the autonomous wishes (leading to personal standards) are not being upheld, and one has a feeling of loss of worth, one's dignity is negatively impacted. Dignity does not just relate to respecting autonomy, but also to the feeling associated with a lack of respect for autonomy. In the case described above, one may still be able to *decide* what one's standards are and what one values (self-directed autonomy), but be unable to *act* on those standards (dignity) or have those standards somehow infringed

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26. Ibid.

27. Jane Haddock, "Towards Further Clarification of the Concept of 'Dignity,'" *Journal of Advanced Nursing* 24, no. 5 (1996): 924–931.

and hence feel a sense of lessened value or worth. The difference is subtle, yet I think is significant enough to consider each concept distinctly.<sup>28</sup>

Is dignity something that is completely subjective, based on a personal experience of standards and convictions? Dignity as described above, focuses on personal standards and convictions, whereas others have argued that we not only have this ascribed dignity, but also an intrinsic sense of dignity.<sup>29</sup> This concept of dignity is less clear than the ascribed sense, but allows each person to have intrinsic worth, in virtue of being a person (often used in a religious context) – this intrinsic dignity may collapse into respect for persons. Kant describes this sense of dignity as follows: “i.e., a worth which has no price, no equivalent for which the object of valuation (*aestimii*) could be exchanged.”<sup>30</sup> Sulmasy further describes intrinsic dignity:

By intrinsic dignity, I mean that worth or value that people have simply because they are human, not by virtue of any social standing, ability to evoke admiration, or any particular set of talents, skills, or powers. Intrinsic dignity is the value that human beings have simply by virtue of the fact that they are human beings. Thus we say that racism is an offense against human dignity. Used this way, dignity designates a value not conferred or created by human choices, individual or collective, but is prior to human attribution.<sup>31</sup>

Sulmasy describes the ascribed/attributed form of dignity as follows:

By attributed dignity, I mean that worth or value that human beings confer upon others by acts of attribution. The act of conferring this worth or value may be accomplished individually or communally, but it always involves a choice.

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28. Some might argue that autonomy is not only reflecting on and deciding on one’s values, wishes and beliefs, as often described in bioethics. It could also include the freedom to act on these values, wishes and beliefs. This wider definition of autonomy can ultimately include dignity as I have described above, and can be violated leading to a feeling of lessened worth. As long as this concept is captured in the framework regarding deception, I am content with either interpretation.

29. See, for example, Daniel P. Sulmasy, “Dignity and Bioethics: History, Theory, and Selected Applications,” in *Human Dignity and Bioethics: Essays Commissioned by the President’s Council on Bioethics* (Washington D.C.: The President’s Council on Bioethics, 2008), [http://bioethics.georgetown.edu/pcbe/reports/human\\_dignity/chapter18.html](http://bioethics.georgetown.edu/pcbe/reports/human_dignity/chapter18.html).

30. Immanuel Kant, “The Metaphysics of Morals, Part II: The Metaphysical Principles of Virtue,” in *Ethical Philosophy*, trans. James W. Ellington (Indianapolis, Indiana: Hackett, 1983), 80–81.

31. Sulmasy, “Dignity and Bioethics.”

Attributed dignity is, in a sense, created. It constitutes a conventional form of value. Thus, we attribute worth or value to those we consider to be dignitaries, those we admire, those who carry themselves in a particular way, or those who have certain talents, skills, or powers. We can even attribute worth or value to ourselves using this word.<sup>32</sup>

Hence, ascribed dignity is something that can be positively or negatively influenced; it can be fostered or harmed. Ascribed dignity can also be impacted by others, and affected or changed by oneself. In this quotation, Sulmasy discusses not only the dignity that we ascribe to ourselves, but also the dignity that is ascribed to us by others – for example, consider a dignitary, or someone who is given a special dignified status in virtue of one’s position. I believe that these two notions still require an individual to have some idea of his or her worth, which can be impacted by others, as opposed to completely prescribed or dictated by others. It is also important to note that even though a patient’s condition may improve with the use of deception, her dignity can still be harmed if she would not feel worthy being treated in this kind of way. The patient in this case is not harmed in the sense that she declines or perhaps ever discovers that deception occurred, but is nonetheless harmed through a disrespect of her dignity.<sup>33</sup>

### *Dignity and Deception*

For this section of Chapter Three, I will refer to *dignity* as the ascribed or attributed sense of dignity, as opposed to the intrinsic form, because this is the kind of dignity that can be influenced or affected; intrinsic dignity, however, is static and cannot be harmed or promoted.

How does the concept of ascribed dignity apply to deception cases in healthcare?

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32. Ibid.

33. It is also important to note that there is a practical limit to upholding ascribed dignity in the healthcare system, due to scarce allocation of resources. Healthcare practitioners can do their best to respect the dignity and standards of a patient, yet it may be impossible to respect and be able to fulfill all standards due to resource limitations. However, I believe that healthcare providers are generally able to fulfill personal standards, and are quite accommodating for patients, when possible.

Deception of a patient who has mental capacity can negatively impact her ability to uphold her own standards and her feeling of self-worth dependent on this standard. There may be other cases where deception, for example, in jest with friends, does not allow one to live up to one's self-ascribed standards but one does not experience a feeling of lessened self-worth and, hence, no loss of dignity.

Deceiving patients who don't have capacity often has the goal of allowing the patient to live up to his or her standards in order to regain or continue to have the feeling of satisfaction of doing so. Since dignity involves a personal recognition of one's standards and being able to live up to these standards, then this ascribed sense of dignity reflects a patient-centered approach to addressing healthcare (and other) needs. The patient's experience or perceived lack of respect for one's standards has an enormous impact on her dignity. One must take into account, what are the patient's values and standards and would using deception, for example through covert medication, likely allow this patient to achieve these standards. Not only the outcome is important, but also the means and the methodology used when deceiving and how each unique patient considers the use of deception.

There are of course acts in healthcare where a patient will no longer be able to live up to one's former or previous standards (for example after a severe stroke). In these cases, a patient may have a loss of dignity if the patient experiences these circumstances as a loss of worth, which is completely understandable under these circumstances. As caregivers and healthcare providers, one ought to do one's best under the particular circumstances, to promote (and where possible, restore) dignity. This can often be in the form of helping patients to develop new personal standards and goals after a catastrophic event, such as a stroke.



There are certainly circumstantial barriers to fostering dignity, but regarding deception, what can be done to promote dignity? Understanding the values and standards of the specific patient is important to recognize what one can do to promote dignity. This requires, in cases where patients lack mental capacity, to try to understand the authentic values of the patient – what standards would the patient subscribe to? What would the patient have wanted? Not only does it matter what the patient’s standards are, but also how the patient would feel if able/unable to live up to those standards. If a patient’s wishes were unknown, then caregivers would apply the best interests standard. Understanding the kinds of standards that a patient would want to subscribe to helps to determine how one can respect those standards – and determine the goal(s) of deception.

### **Considerations Set Aside**

#### *Intrinsic Value of Truth*

Michael Lynch in “Deception and the Nature of Truth” argues that we simply prefer the truth, if even it only has “psychological value,” such that it is comforting.<sup>34</sup> Lynch first agrees with Frankfurt’s assessment of deception; we generally have a strong dislike of deception because it interferes with our ability to function within the world.<sup>35</sup> Lynch remarks: “But if even it is not overtly dangerous, it is likely to interfere with one’s plans, to change them, or to simply make them go awry. Either way, we are less likely to get what we want.”<sup>36</sup> In order to achieve our goals and ends, we want to be connected to the world so we can navigate it; cases of mental

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34. Michael Lynch, “Deception and the Nature of Truth,” in *The Philosophy of Deception*, ed. Clancy Martin (Oxford: Oxford University Press, 2009), 188–200.

35. Harry Frankfurt, “On Truth, Lies, and Bullshit,” in *The Philosophy of Deception*, ed. Clancy Martin (Oxford: Oxford University Press, 2009), 37–48.

36. Lynch, “Deception and the Nature of Truth,” 197.

incapacity rob individuals of reality orientation and often of this ability to attain our ends. I have argued that using deception as a means can be useful to re-establish the connection with reality and assist an individual with achieving his or her authentic goals.

Lynch's argument extends beyond the idea of deception as being a negative concept because it interferes with practical consequences. Lynch introduces the following scenario: You are presented with two doors. Behind one door, life continues as normal. However, behind the other door, life would seemingly continue as normal, although your friends and lover actually despise you. They are extremely good at deception, and you will never know which door leads to which life.<sup>37</sup> Lynch argues that nobody would prefer the life of a "fool," if even the appearances of relationships were the same through each door. He remarks that with the choice of door, some may be ambivalent and others would prefer truthful relationships, but doubts that anyone would prefer the life of deception. This argument aims at revealing that we have an intrinsic value for truthful relationships, despite deception preventing us from achieving particular goals or aims.

Hence, one might argue that it is wrong to deceive others, since we value truth intrinsically. Lynch, however, makes an interesting final remark, "Sometimes other things matter more than truth. Thus, more of us would be willing to be deceived, or to deceive ourselves, if we thought that more good than bad would come of it overall, or that the matter was so trivial that the point was essentially moot."<sup>38</sup> Although we value truth intrinsically, such as it is not attached to any other end, this is one value (among many) that guides decision-making, which can be overridden dependent on the situation.

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37. Ibid.

38. Ibid., 198.

This is an important consideration with respect to patients who will likely not recover significantly; consider, for example, patients suffering from severe Alzheimer's disease. In these cases, one must examine whether the patient would have preferred to be re-oriented to the truth (e.g. in cases where the patient's spouse died, and a reminder of this event causes the patient tremendous pain and suffering; often in the mornings she spends hours agonizing over the death of her loved one, once reminded) and the benefits and risks of doing so. A caregiver ought to consider whether a patient living a life with less angst is more appropriate based on his or her authentic desires, wishes and quality of life experiences.

With respect to patients who lack mental capacity, one's ability to discern between what is true and not true is often severely impeded. As Lynch argues, we care deeply about the truth and would want cognitive abilities restored such that we could once again understand and appreciate the truth. If truth matters to us intrinsically, and mental impairment significantly hampers our ability to attain truth, and if a small amount of deception in the short-term could restore the patient's long-term ability to appreciate and understand the truth, then deception could be morally justifiable. I will return to this argument in the consequentialist section. Hence, it may be acceptable to use deception in order to be in a state in which one is capable of appreciating the truth and general perceived reality. One major aim of general medicine and psychiatry is to treat individuals such that they are able to achieve their own goals in accordance with their values and beliefs. Perpetuating a misinformed and distorted reality can harm our intrinsic value of truth much more than a short-term and well-meaning act of deception. Truth is something that we deeply value and for these reasons it often is and feels wrong to use deception. However, in cases of deceiving individuals suffering from mental impairment, the act itself can lead to increased correspondence with truth, if the goal is to

restore cognitive abilities and meaningful or substantial autonomy. Arguably, deception is justifiable under specific circumstances, which I will describe in further detail in the next chapter. Hence, we can set aside this notion, as it can either be incorporated in the autonomous wishes of a patient or other competing morally relevant features can override it.

### *Universality and Deception*

Universality is often considered as Kant's first formulation of the categorical imperative: "act only in accordance with that maxim through which you can at the same time will that it become a universal law."<sup>39</sup> One formulates a maxim according to reason, and wills that this maxim is how every rational person ought to act. If this law can be rationally applicable to all persons, then it is morally required of us.

Having universal laws prevents people from merely acting on desires or intuitions. It requires that moral agents are *consistent* in both applying their standards to themselves and to others. Universality aims at thwarting selfishness, favouritism and capricious actions. It further aims at generalizability and moving from a specific case to being able to apply one's standards and principles to all like-cases.

When considering universality in contemporary bioethics, the term is often used in the context of justice in global bioethics – how we ought to treat others beyond the limits of national borders. Universality addresses the uneven distributions of goods and questions of global social justice, for example.<sup>40</sup>

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39. Immanuel Kant, *Groundwork for the Metaphysics of Morals*, ed. and trans. Allen W. Wood (New Haven: Yale University Press, 2002), 37.

40. For example, see Mary C. Rawlinson and Anne Donchin, "The Quest for Universality: Reflections on the Universal Draft Declaration on Bioethics and Human Rights," *Developing World Bioethics* 5, no. 3 (2005): 258–266.

Ruth Macklin is a strong proponent of universalism applied to biomedical ethics. She makes the distinction between universalism and absolutism. Absolutism involves strong binding rules that do *not* have exceptions, such as “do not lie” and “always keep promises.”<sup>41</sup> Whereas universalist ethics maintains that there exist fundamental ethical principles, for which exceptions can be made.<sup>42</sup> In Chapter Five, I will argue why the principlist approach (also considered a universalist approach) is currently the best approach to biomedical ethics, as well as provide a critique of its present form, with suggestions for improvement.

These general ethical principles need not be applied and strictly followed in every case. Rather, the principles can come into conflict and one ought to weigh and balance the principles to determine what one should do.<sup>43</sup> The principles are *prima facie* rules that can be privileged over one another, depending on the specific case. In Chapter Four, I will discuss how we can weigh and balance the competing values and principles in a non-arbitrary way. For example, coherence is a method that aims at consistency among morally relevant features, while not rigidly appealing to former cases.

In light of these remarks on universality, what can be said of deception and universality? Ensuring consistency regarding decision-making is important, but consistency of what? In the next chapter I will argue that consistency between morally relevant features across cases is what matters.

From a strict orthodox Kantian perspective, any kind of deception in any case would not pass the logical consistency test. If we apply a universal standard to all, then nobody would

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41. Ruth Macklin, *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine* (Oxford University Press, 1999), 112.

42. Ibid.

43. Ross, *The Right and the Good*.

believe anyone else, and deception would not be logically consistent or likely possible due to a general scepticism and distrust among people.

Applying this concept to healthcare and deception, I have already discussed at great length the concerns with deception and trust. If patients realized that deception was being used in healthcare, then patients would be more reluctant to seek care. An example where deceptive healthcare practices have caused patient populations to be afraid and extremely reluctant to seek future care includes the great syphilis scandal in health research – the Tuskegee Syphilis Study.<sup>44</sup> In this study from 1932-1972, African American men thought that they were receiving free healthcare, whereas they were injected with syphilis in the name of clinical research to study the natural progression of the disease without treatment.

Other experiments and historical atrocities in healthcare include experimentation on prison inmates throughout the twentieth century, including injecting inmates with cancerous cells to determine their prognostic trajectory.<sup>45</sup> These healthcare experiments were based on the intention to increase knowledge about deadly conditions and to improve overall healthcare through deceptive and morally atrocious means – essentially sacrificing a few members of society (members who were perceived to have less value) for the greater good.

As you may note, the practice of deception in healthcare that I propose is quite different. The act of deception is aimed at increasing the quality of life for each unique patient, given his or her personal values and reducing the risks of harms (including to trust). Especially given the patient population to which my research applies, those who lack mental capacity often suffer from mental illnesses that can cause significant delusions, whereby acts of

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44. Vicki S. Freimuth et al., “African Americans’ Views on Research and the Tuskegee Syphilis Study,” *Social Science and Medicine* 52, no. 5 (n.d.): 797–808.

45. Allen M. Hornblum, “They Were Cheap and Available: Prisoners as Research Subjects in Twentieth Century America,” *BMJ* 315, no. 7120 (November 29, 1997): 1437–1441.

deception may cause further scepticism and even alienation of these groups. One might argue, however, that if the practice were transparent and the reasons and process for when deception is morally acceptable is made clear to patients and the public at large, then there would be less concern with its use. It would also be important to ensure that there are checks and balances used when employing deception to ensure that deception is not being used inappropriately.

It is unreasonable to think that we can abide by all duties, all the time. There are instances when following autonomy will cause harm, for example. I will not discuss universality in the rigid Kantian sense, but rather focus on consistency between like cases in Chapter Four and also in Chapter Five. I am setting aside universality in its strictest form, as my aim to create a policy and decision making-framework must be practical in order to be employed. Hence, I reject the orthodox Kantian perspective, as I believe that there are situations where deception can be morally justified when balancing the relevant moral principles. Nonetheless, I do believe that it is important to be transparent about the process used, to avoid the kind of scepticism of the healthcare system that can occur if deception continues to be a secretive process without better guidelines around its use.

#### *Consequentialist Factors*

As with the deontological section in this chapter, I will not be taking a particular consequentialist position, but I will instead discuss several factors, commonly considered consequentialist, relevant to deception in caregiving. These factors will help to enrich the discussion of when deception in caregiving is a morally defensible or indefensible alternative for caregivers. The third section in this chapter will consider factors regarding virtue ethics and character.

## Factors to be Weighed

### *Pressures on Healthcare Providers and Other Caregivers*

Realistically, healthcare providers face greater and greater cutbacks in resources and staffing, resulting in more duties to be performed in less time. Their roles have also changed significantly from spending direct face-to-face time with patients providing holistic care to fulfilling standardized organizational requirements, such as completing more paperwork.<sup>46</sup> Studies show that with increasing workload, patient safety becomes a higher risk as staff are more prone to making mistakes and are simply unable to keep up with all of their duties.<sup>47</sup> Increased time and workload pressures on staff make deception an appealing option to caregivers, since it alleviates the need to spend time negotiating with patients, watching patients to ensure medication is taken, utilizing more aggressive means like physical restraints and so forth.

Healthcare providers must assist a significant number of patients on any given shift, and their realistic duty is to all of their patients, as opposed to spending all their time with one or just a few patient(s); deception may be justifiable given a utilitarian consideration of increasing the overall well-being of the greatest number, as opposed to doing one's best for one patient, especially given the potential burnout associated with constantly trying to negotiate with patients who would benefit significantly from the medication.<sup>48</sup> Further burnout and

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46. Sean P. Clarke and Linda H. Aiken, "Failure to Rescue: Needless Deaths Are Prime Examples of the Need for More Nurses at the Bedside," *American Journal of Nursing* 103, no. 1 (January 2003): 42–47.

47. Ann E. Rogers et al., "The Working Hours of Hospital Staff Nurses and Patient Safety," *Health Affairs* 23, no. 4 (July 1, 2004): 202–212.

48. Matthew D. McHugh et al., "Nurses' Widespread Job Dissatisfaction, Burnout, and Frustration with Health Benefits Signal Problems for Patient Care," *Health Affairs (Project Hope)* 30, no. 2 (February 2011): 202–10.



distress may be observed when reminding patients with advanced Alzheimer's about a loved one who has died.

Distributive justice might also require one to spend one's time assisting more than one patient if resources are limited. It would be easy to say that one ought to increase resources, but an ethical theory needs to be practical to actually require action from us, and increasing resources is not currently feasible. Being realistic and efficient is important, but it is dangerous to "cut corners" simply for efficiency. Due process is important and respecting each patient is necessary, especially given Canadian healthcare's commitment to patient- or client-centered care. In Chapter Four, I will also discuss the relevant features important for an ethical theory, and the importance of practicality.

There simply is not enough time available to negotiate with patients to take their medication in every instance. Other alternatives to deception include, as I have described in Chapter Two, restraints to administer medication, full disclosure of the truth and completing an advance care planning about these issues during moments of lucidity. If a patient is clearly resolved to not take medication, for example, caregivers ought to ask a series of questions. The most significant question is trying to determine *why* the patient is refusing medication. The following list of questions might assist with determining this, for example: Why do you not want to take your medication and do you experience any side effects from the medication; how does this make you feel?

A caregiver should explore whether any of these questions and perhaps others can be addressed, still allowing the patient to take the medication and experience the positive outcomes from doing so. As described earlier from the Sheffield Care Homes Organization, there are many other considerations to first explore in terms of the patient, for example, not

understanding what to do with medication, finding medication unpleasant to tasted and so forth.<sup>49</sup>

It may seem that asking these questions will take just as much time as negotiating with a patient to just take the medication – but this is not so. In asking these questions, and addressing these concerns, hopefully a patient will feel better about taking the medication without having to, for example, feel unwanted side-effects. The patient may still refuse the medication because of delirium, psychosis etc. and, at this point, covert medication may be ethically defensible, but at least due process has occurred and a reasonable attempt has been made to try to address any concerns or discomfort with taking the medication. Frequent re-evaluation of capacity, side-effects and the need for covert medication ought to occur.

#### *Additional Pressures on Non-Healthcare Provider Caregivers*

I will now address the kinds of issues that this sub-group of caregivers experience, most often family members and friends/neighbours. To put caregiving in Canada into perspective, from the most recent Statistics Canada data from 2012, approximately 8.1 million Canadians are considered to be caregivers of a family member or loved one. Statistics Canada defines a caregiver as: “those aged 15 years and older providing help or care within the past 12 months to either: 1) someone with a long-term health condition or a physical or mental disability, or 2) someone with problems related to aging.”<sup>50</sup>

*Caregiver burden* is a common occurrence for those who look after another person with either or both a physical/mental illness. I personally find this expression troublesome, as the

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49. Sheffield Care Homes (NHS Foundation Trust), “Good Practice Guidance on Covert Administration of Medication.”

50. Maire Sinha, “Portrait of Caregivers, 2012,” Government of Canada, *Spotlight on Canadians: Results from the General Social Survey*, Statistics Canada, Government of Canada, (September 10, 2013), <http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm>.

word *burden* has many negative connotations, which can actually lead to guilt for those who are being looked after.<sup>51</sup> Nonetheless, this is the commonly held expression in healthcare, and I will use it for consistency.

First, there is much literature on caregiver burnout and distress for caregivers in the community who look after a loved one with dementia. Gitlin et al. remark:

Caring for individuals suffering from dementia has profound consequences for family caregivers. Potential stressors associated with family caregiving are numerous and may include managing behavioral disturbances, attending to physical needs, and providing seemingly constant vigilance.<sup>52</sup>

Looking after someone who suffers from dementia requires much time and personal energy.

Gitlin et al. further remark:

The effects of these stressors on family caregivers can be catastrophic. Family caregiving has been associated with increased levels of depression and anxiety as well as higher use of psychoactive medications, poorer self-reported physical health, compromised immune function, and increased mortality.<sup>53</sup>

Caregivers have enormous pressures to look after not only the person with dementia, but also themselves and others who are under their care. Caregivers are often those looking after a parent, as well as providing for children.<sup>54</sup>

In a web-based survey completed by 398 individuals between September 15 and November 5 of 2006, the Canadian Alzheimer's Society collected data on burnout associated with caregivers looking after a person with Alzheimer's disease.<sup>55</sup> Caregivers are often family

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51. Christine J. McPherson et al., "Feeling Like a Burden to Others: A Systematic Review Focusing on the End of Life," *Palliative Medicine* 21, no. 2 (March 2007): 115–128.

52. Laura N. Gitlin et al., "Effect of Multicomponent Interventions on Caregiver Burden and Depression: The REACH Multisite Initiative at 6-Month Follow-Up," *Psychology and Aging* 18, no. 3 (September 2003): 362.

53. Ibid.

54. Sinha, "Portrait of Caregivers, 2012."

55. Sandra E. Black et al., "Canadian Alzheimer's Disease Caregiver Survey: Baby-Boomer Caregivers and Burden of Care," *International Journal of Geriatric Psychiatry* 25, no. 8 (August 1, 2010): 807–813.

members (most often women) and face many different emotional, psychological, physical and financial stresses when caring for someone with dementia. Caregivers often struggle with depression, reaching rates of approximately 83%, whereas the general population over the age of 65 has a rate of approximately 7%.<sup>56</sup> Caregivers are also more socially isolated and physically restricted when constantly caring for someone with dementia, which can lead to depression.<sup>57</sup> This also places caregivers at a higher risk for health concerns, as they are restricted and again more prone to depression.

There are some supports available to caregivers in the community, such as respite programs, including adult day programs and support groups, which assist caregivers substantially and often increase quality of life for patients and for caregivers. Other options include placing the person with dementia in a nursing home or long-term care facility, when appropriate. Although, these processes can involve significant financial contributions, as well as lengthy wait-lists given the demand for long-term care with a shortage of beds, as well as the Ontario Government's focus on keeping patients at home as long as possible.<sup>58</sup> Hence, with a growing elderly population and limited healthcare resources, caregiver burden is a significant concern.

As with caregivers of people with dementia, caregivers of people with mental illness (and other illnesses) face similar pressures. In a survey completed by 697 caregivers and 439 patients who have schizophrenia, the following list of negative impacts of the illness on the patient and caregiver(s) were disclosed:

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56. Ibid., 809.

57. Ibid.

58. Emma Bartfay and Wally J. Bartfay, "Quality-of-Life Outcomes Among Alzheimer's Disease Family Caregivers Following Community-Based Intervention," *Western Journal of Nursing Research* 35, no. 1 (January 1, 2013): 98–116.

- (a) a decline in family social outings and activities;
- (b) increase in disagreements, disputes or fights among family members;
- (c) depression in other family members;
- (d) embarrassment of other family members;
- (e) economic difficulties;
- (f) delay or cancellation of vacation plans;
- (g) loss of self-esteem or confidence in other family members;
- (h) decline in the work or school performance of other family members;
- (i) increase in alcohol use;
- (j) separation from a spouse.<sup>59</sup>

Awad and Lakshmi further remark on the difficulty of addressing caregiver burden:

The complexity of the ‘burden of care’ concept and many of its components that sometimes defy accurate enumeration may have discouraged researchers from investigating such important subjects. While it is possible to cost tangible components of family expenses such as time lost, transportation, food, clothing, housing, recreation, medical care, insurance, debts, etc., it is difficult to put a monetary value on psychological and emotional issues such as anguish, distress, feelings of loss, stigma, low self-esteem and absence of a productive and self-fulfilling role.<sup>60</sup>

These various consequences create enormous pressures on caregivers. Caregivers are under significant stress from financial, psychological and emotional pressures, in situations when they are trying to do the best they can for their loved one.<sup>61</sup>

The pressures that I have listed and discussed in this section consider factors why one might be inclined to use deception as a tempting option for making caregiving more practical

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59. A. George Awad and Lakshmi N. P. Voruganti, “The Burden of Schizophrenia on Caregivers,” *PharmacoEconomics* 26, no. 2 (February 1, 2008): 155.

60. *Ibid.*, 156.

61. Jana C. Saunders, “Families Living with Severe Mental Illness: A Literature Review,” *Issues in Mental Health Nursing* 24, no. 2 (January 2003): 175–198.

and effective. This occurs especially in light of a caregiver's ability to continue to care for a loved one, likely resulting in the potential consequences listed above. For example, a caregiver whose patient constantly asks after her partner's death will not have to spend the time and energy negotiating with and comforting her, when this time can be spent assisting others and fulfilling other important duties.

In exploring the reasons why one might feel justified to use deception as opposed to other means, I have discussed several consequentialist arguments about pressures on both healthcare workers and on caregivers more broadly. There are competing interests in society (including the interests of all patients, rather than just one or a few) and if other alternatives were to be employed, such as negotiation, then caregivers may not be able to continue to provide and care for others under their care and/or for themselves.

I have not provided clear responses as to what one can do about these kinds of pressures, which can ultimately be reasons why caregivers would find deception an ethically appealing position. In Chapter Four, I will consider all of these factors and provide a framework to help guide when it is morally defensible to deceive patients, and when it is morally indefensible to do so.

#### *Virtue Ethics Factors*

The final section of this chapter will address some virtue ethics concerns with deception in the caregiving environment. Begley remarks:

The word 'virtue' is derived from the ancient Greek notion *arete* which differed significantly from a modern understanding of the concept. The Greek word *arete* (virtue) means *excellence* in relation to a skill or trait of character and is linked to function... This requires excellence in practical skills, in theoretical

knowledge and in moral virtue (excellence of character). Virtues can also be described as attributes, character traits or excellences of character.<sup>62</sup>

First, the following are the virtues that Beauchamp and Childress describe as important for caregivers: compassion, discernment, trustworthiness, integrity and conscientiousness. I will briefly discuss these virtues and then discuss other virtues required of a healthcare professional. Lastly, I will relate the discussion of virtues to the topic of deception in caregiving. Note that many of the virtues espoused for healthcare providers and in this body of literature are virtues that one can argue are integral to the character of any caregiver more broadly.

### **Factors to be Weighed**

I will briefly provide an overview for the type of character that Beauchamp and Childress encourage for healthcare providers. Compassion is the ability to care for and empathize with those for whom one is caring. Discernment is having good judgment and being able to reflect carefully on situations to assess, weigh and balance competing and various considerations; it involves understanding the principles and knowing how to apply them to particular situations – I will return to this idea in Chapter Four. Trustworthiness can have multiple meanings, as I’ve detailed in Chapter One and Chapter Two. Beauchamp and Childress refer to trustworthiness as believing that the healthcare provider will act in the best interests of the patient, and trust that the caregiver is competent and has good motivations and moral character – I have already argued that there are multiple meanings and ways that one can view the concept of trust in a therapeutic and care-giving relationship, including both truth-telling and acting in the patient’s best interests reliably – these notions can impact individual patients and also trust in the

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62. Ann M. Begley, “Truth-Telling, Honesty and Compassion: A Virtue-Based Exploration of a Dilemma in Practice,” *International Journal of Nursing Practice* 14, no. 5 (October 2008): 336–337.

healthcare system at large. Integrity is acting on particular standards, including personal, professional, legal, ethical and so forth. Often contrasted with integrity is hypocrisy, which is acting differently to the standards one claims to uphold. Finally, Beauchamp and Childress highlight conscientiousness as an important value for care-givers; conscientiousness is intending to do what is right and taking reasonable effort in order to do the right thing, including due diligence on behalf of the caregiver.<sup>63</sup>

The Accreditation Council of Graduate Medical Education (ACGME) outlines the general competencies for US medical residents, and it focuses on what it means to be a *good professional*. This formal professionalism uses a virtue ethics framework to highlight the various virtues of physicians.<sup>64</sup> Doukas further remarks that: “Hafferty more directly argues that the ‘hidden curriculum’ requires incorporation of virtue ethics as ‘necessary for the practice of ethical medicine.’”<sup>65</sup> Doukas describes the hidden curriculum as helping to facilitate healthcare and caregiving, allowing the caregiver to conduct his or her art. These competencies include “fidelity to trust, self-effacement, and practical wisdom.”<sup>66</sup> The choice of word *fidelity* is interesting, as it represents other concepts like loyalty, reliability, trustworthiness, faithfulness and dependability. As with the word *trust*, one needs to ask further questions, such as trust of (or based on) *what* and trust in *whom* (e.g. the physician, caregiver, healthcare system, etc.). It is also interesting to note the overlap between Beauchamp and Childress’ notion of discernment and conscientiousness and the ACGME standard of practical

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63. Beauchamp and Childress, *Principles of Biomedical Ethics*, 32–45.

64. David J. Doukas, “Where Is the Virtue in Professionalism?,” *Cambridge Quarterly of Healthcare Ethics* 12, no. 02 (2003): 147.

65. *Ibid.*, 148.

66. *Ibid.*



wisdom, aimed at incorporating these notions. Other virtues outlined in this document include cultural sensitivity, respect, accountability, openness, confidentiality and responsiveness.<sup>67</sup> These additional virtues highlight the importance of maintaining relationships with patients, as well as being sensitive to their particular values and wishes.

From both Beauchamp and Childress and the ACGME standards, the kind of character that is praised or seen as being ethically desirable in healthcare is evident. Given that these various virtues are commonly considered as important for caregivers, how might one approach the issue of deception? It is important to strive towards being this kind of caregiver, however, as with the principlist approach, one might not be able to be fully virtuous – to exhibit all virtues consistently and coherently. Similar to principlism, the virtues are *prima facie* important, and may practically come into conflict. The main virtue that is at risk of being violated in cases of deception is that of veracity or truthfulness. One can imagine that veracity will conflict with other virtues, such as being compassionate. Caregivers ought to consider the specific circumstances of each individual patient to weigh and balance which alternative is best for the patient and perhaps which alternative best represents a fulsome virtuous caregiver, striving to exhibit the most virtuous characteristics as coherently possible. This process also requires employing the virtues listed above, such as discernment and conscientiousness.

### **Factors to Set Aside**

Two authors, Anthony Tuckett and Ann Begley each offer different virtue ethics approaches to deception in healthcare. These two articles specifically focus on a virtue ethics approach to healthcare in cases of deception, which is why I have raised them in this section. Both authors argue that the conflict in cases of deception occurs between truth-telling and compassion.

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67. *Ibid.*, 150–151.

However, each has a different view on how the conflict ought to be resolved from a virtue ethics perspective. I will briefly discuss each argument and discuss why these factors can be set aside, in light of the comprehensive account of virtues that I discussed in the previous section.

Tuckett argues that caregivers ought to take the Good Samaritan parable as exemplary of good action. The Good Samaritan aims to selflessly assist a man who was beaten and left for dead. The Samaritan defies traditional religious, cultural and political boundaries by aiding someone from a different (lower) class in society. The act is iconized as an act of pure compassion and care towards a complete stranger. Tuckett argues that the Good Samaritan parable is the ideal of caregivers, being compassionate towards others, including strangers, without expecting anything in return.<sup>68</sup> The conflict in Tuckett's case occurs between truth-telling and compassion. The article emphasizes the importance of the prima facie nature of truth-telling. Tuckett focuses on truth-telling to patients who are dying and who have mental capacity – he remarks that we ought to be sensitive in disclosing information. He uses a *titration* analogy, referring to slowing disclosing information to understand and recognize how much the patient and family can actually handle; this approach encourages the use of euphemisms and half-truths to protect patients.<sup>69</sup> Tuckett ultimately argues that compassion should outweigh one's duty of veracity.

There is however, much literature that argues the use of euphemisms should be avoided in end-of-life and other kinds of care, and a direct, open approach is much more desirable, taking into consideration how much information each patient is able to understand and

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68. Anthony Tuckett, "Nursing Practice: Compassionate Deception and the Good Samaritan," *Nursing Ethics* 6, no. 5 (September 1, 1999): 383–389.

69. Ibid.

appreciate at a given time.<sup>70</sup> Nonetheless, I will first discuss the second account, Begley's account, and then argue that these two analyses of virtue ethics and deception are inadequate.

Begley similarly argues that compassion ought to outweigh the virtue of truth-telling. She first recognizes the challenge posed by many who hold a position contrary to virtue ethics – it lacks the kind of systematicity offered by other normative theories, such as utilitarianism and deontology. She then proceeds to remark that virtue ethics is based on experience, development through observation and working with mentors who espouse these virtues in daily practice while focusing on the complexity of circumstances.<sup>71</sup>

Regarding character and deception in nursing practice, Begley highlights cases of deception regarding lying to patients about a diagnosis to relieve the stress and burden of fear of dying. She indicates that there exists a conflict between truth-telling (trustworthiness/honesty) and being compassionate. She remarks:

Some health-care professionals consider withholding the truth from patients to be absolutely morally wrong in all circumstances. Others feel strongly that although deliberate lying cannot be justified, withholding the truth rather than destroy hope, which is precious and therapeutic, can be justified in the interests of compassion and without the arrogance or paternalism often associated with these decisions.<sup>72</sup>

In her article, Begley describes the importance of exploring the values of each specific patient to determine what is best in each situation, guided by the virtues, which may conflict; the conflict is ultimately resolved through deep reflection and phronesis regarding what the patient

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70. See for example, Thomas Martin Ratcliffe, "Healthcare Providers Need to Improve Communication with Patients Who Have Heart Failure," *British Journal of General Practice* 57, no. 536 (March 1, 2007): 180–182.

71. Begley, "Truth-Telling, Honesty and Compassion," 338.

72. *Ibid.*, 338–339.

would want to be told or not told. Nonetheless, the focus is on being a present and compassionate caregiver.<sup>73</sup>

Begley also reflects on the concern that a virtuous person ought to always be truthful and attempt to live each virtue to its fullest, as opposed to picking and choosing which virtue best relates to a specific situation. This concern relates to Aristotelian virtue ethics, which states that one cannot be truly virtuous without espousing all the virtues. Begley, however, argues that virtues will come into conflict and that a virtue ethics approach needs to be practical and allow for prima facie virtues to outweigh one another in specific instances.<sup>74</sup>

I think that Begley is on the right track when arguing that an ethical theory or framework needs to be practical for real situations and circumstances, as well as arguing that taking into consideration the patient's wishes and values may affect how one acts, especially in cases of truth-telling. However, both Tuckett and Begley focus mainly, and arguably too narrowly, on the two virtues of truth-telling (as honesty) and compassion. Begley does additionally briefly highlight some other virtues, including practical wisdom and discernment in these kinds of cases.<sup>75</sup>

In the *factors to be considered* part of this section, I discussed a comprehensive list of virtues involved in caregiving more broadly, but also applicable to cases of deception. I believe that both Tuckett and Begley over-simplify the issue of deception in caregiving by seemingly choosing between one of two competing virtues – truth-telling and compassion. Although these virtues are important, discernment and one's ability to practically reason through the morally relevant features are necessary. In Chapter Four I provide a framework to help caregivers to be

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73. Begley, "Truth-Telling, Honesty and Compassion."

74. Ibid., 341.

75. Ibid., 340.

able to discern whether deception is morally defensible or indefensible. Discernment and prudence on their own are not entirely useful, unless one has constructed a framework to think through the morally relevant kinds of considerations. In the previous chapters and throughout this chapter, I provide many different morally relevant factors to consider through discernment. In Chapter Four I will also discuss how one can use discernment in a non-arbitrary way. Hence, the conflict is much more complex than presented by Tuckett and Begley.

A final concern involves building character more generally, which these articles did not address – what kind of person would be willing to and actually participate in deceiving patients? What does this say about one’s broader character? Once one is willing to deceive patients, does this make it easier to deceive patients in future situations, and would this lead to a slippery slope of abuse of deception in healthcare? As I’ve discussed in detail in the introduction and Chapter One, the abuse of deception in healthcare is already a serious problem. Although I do not wish to argue for a harm reduction approach, I believe that having a clear framework to explain when deception is morally defensible and when it is indefensible is necessary to avoid snap judgments or malicious intentions for certain cases of deception.<sup>76</sup> If even deception were used, at least through the framework it would be used for the right reasons, under the right circumstances. If caregivers are aware of the parameters when to use

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76. Situationism offers a critique of virtue ethics. Kamtekar describes how social psychology claims to debunk the notion that people tend to react to like-situations alike, essentially having consistency in their personal traits across cases. Rather, individuals judge each situation uniquely and make decisions based on the particular morally relevant features at hand, oftentimes highly influenced by behavioural norms. Kamtekar also cites the work of Gilbert Harman, who argues that psychology shows that we do not have particular character traits that are stable over time, which calls into question whether we can (and should) try to build or shape and mould character over time. Kamtekar ultimately argues that these psychological findings are somewhat superficial, not exploring character at a deeper level – such as through the way one reasons, providing motivation for action and finding consistency among traits when making decisions. I don’t want to stray too far from the virtue ethics analysis in this section in responding to critiques of virtue ethics, but it is important to note that developing one’s character and aiming to act consistently does not always coincide with how people actually judge moral situations – which is not to say that this is how they *ought* to make decisions or at least ought to aim to make decisions. See: Rachana Kamtekar, “Situationism and Virtue Ethics on the Content of Our Character,” *Ethics* 114, no. 3 (April 1, 2004): 458–91.

deception and when to not use deception, then they are arguably more conscious of morality, as opposed to being more inclined to deceive more generally in other cases.

Given all of these considerations, what can virtue ethics add to the discussion of the moral defensibility of deception in bioethics? Virtue ethics provides further strength to the values already discussed through the biomedical ethics principles – those of being compassionate through beneficence, and being truthful through trust (although I have described other forms of enhancing trust) and the need to be thoughtful and prudent in decision-making. In the next chapter, I will present a decision-making framework at both the organizational and clinical levels that includes the necessary morally relevant factors such that caregivers can be prudent when thinking through the dilemma of deception in caregiving.

### **Conclusions**

In this chapter, I have argued that there are many different considerations and factors beyond Beauchamp and Childress' traditional biomedical ethics principlist account that ought to be involved in the decision-making process for an ethically defensible position for deception in caregiving. These factors include deontological concepts, such as the intrinsic value of truth, dignity, universality and various duties and obligations of caregivers. I further discussed several important pressures and burdens faced by both healthcare providers and caregivers in the community more broadly, as consequentialist factors to support deception. I concluded this chapter with a discussion of commonly espoused virtues of caregivers, those encouraged by both Beauchamp and Childress and the ACGME, and how they might apply to cases of deception in caregiving.

It is my aim that my philosophical account will clearly articulate the morally relevant features for cases of deception and how we ought to weigh and balance these in particular cases; I will provide a detailed account of how this can be done in the proceeding chapter. My objective will be to support consistency between cases, but also to allow flexibility dependent on the specific moral features of each unique patient's circumstances.

## **Chapter 4**

### **Weighing and Balancing Factors**

Before continuing with the next chapter, I will briefly summarize my thesis project thus far. In Chapter One, I explored the current academic landscape regarding the morality of deception in caregiving. I also provided statistics on the prevalence of deception in caregiving and caregivers' self-articulated reasons for its use. I redefined the problem of deception as being more complex than weighing and balancing either only autonomy and beneficence or autonomy and trust. I outlined each of the traditional bioethics principles to consider as an alternative to the traditional debates surrounding the moral dilemma of deception in caregiving. In Chapter Two I discussed several alternatives to deception, including the use of restraints, advance care planning and absolute truth-telling. I argued that although these alternatives may be more appropriate than deception in certain circumstances, deception might be the morally preferable option in other circumstances, for which I will provide a framework in this chapter. However, before detailing the circumstances that allow for deception, I explored and discussed additional morally relevant factors when deciding whether or not to use deception in the third chapter. These factors include the legal and professional constraints on healthcare providers, and considerations that we should explore from different moral theories, including consequentialism, deontology and virtue ethics.

In this chapter, I will respond to the following questions. What ought we do with these factors? How can we coherently specify them, then weigh and balance these considerations in a practical, justified and non-arbitrary manner? What is the appropriate follow-up regarding re-assessing the use of deception and what kind of documentation is necessary? This chapter is divided in three sections. First, I will provide a comprehensive account at both the



organizational (policy) and clinical (patient-specific) levels on how to work through these ethical issues, followed by a methodological way of weighing and balancing the considerations associated with deception in caregiving. Lastly, I will discuss additional requirements for the implementation of deception as a treatment conduit.

### **A Process for Specification, Weighing and Balancing**

In the following section, I will discuss how we can consider deception at both the organizational and the clinical levels. I will provide a decision-making framework to create and implement a policy and a clinical decision-making process for deciding which cases of deception are morally defensible or indefensible. I use the considerations and factors described in Chapter One and Chapter Three to weigh and balance factors why, in certain situations, deception is morally impermissible at the organizational level. I further argue that there are other conditions that ought to be met before proceeding to the next level – the clinical level. I specify the broader principles and values described in previous chapters to cases of deception at the organizational level to develop broad cases when deception ought and ought not be used. The final section focuses on clinical conditions and on further specifications to analyze individual cases and to decide whether deception is ultimately morally defensible or indefensible in unique cases.

#### *Organizational Policy*

What would a policy look like at an organizational level regarding deception? Should deception be considered at all, given the grave risk of breaking trust within society if it were known that deceptive acts were occurring? Should an organization take the position that it is completely morally indefensible to use deception in any case?

In light of the various considerations throughout the preceding chapters, I have determined six major morally relevant factors to consider when deciding whether or not deception ought to be used at an organizational level. Even though the categories relate to specific patient experiences, we can use them to group together the kinds of situations when deception would be morally permissible and those when it would be morally indefensible. The categories are as follows: mental capacity, compliance with treatment (when applicable), substantive risk of distrust, significant chance of benefit, disclosure (if possible) and controlled environments. I will discuss each of these considerations as either a constraint or necessary condition on the use of deception, and argue why each is included in its respective category. It might be necessary to work through the clinical framework to help populate and specify whether the particular case fits within a moral constraint or necessary condition. For example, one might need to discuss the harms associated with a particular case to understand whether there will be a significant risk of distrust.

In this section I will refer to morally impermissible/reprehensible/indefensible acts to mean those that one ought not perform. Morally permissible acts are those that are not prohibited, but are required to be considered further under the scrutiny of the clinical framework for assessing deception. After the assessment through the clinical framework, one can determine whether the act is morally defensible. I will argue under each category why each factor is either a constraint or a necessary condition referring back to the morally relevant factors I have gathered in preceding chapters.

At the organizational or policy level, it is more evident that certain general constraints and necessary conditions can be clearly stated given the likely consequences of each. At the organizational level, certain factors tip the scale more clearly against the use of deception

given their significant negative consequences. As such, there are also necessary conditions when considering deception that ought to be met. Hence, under each constraint and necessary condition, I will argue why these factors make the use of deception either more evidently indefensible/ defensible. In the clinical decision-making framework, however, it is less clear how each morally relevant factor contributes to the moral indefensibility/defensibility until more information is gathered regarding each specific patient. Once the broader bioethics principles are further specified in the clinical decision-making process, then weighing and balancing are necessary.

### **Constraints on Deception**

Constraints are non-negotiable excluding factors. If the act of deception could reasonably involve the constraint, then deception is morally impermissible. First, I will discuss having mental capacity to make treatment and other decisions as being another constraint for the use of deception in caregiving. I will then discuss compliance with treatment (when applicable) as being another constraint and lastly I will reflect on substantive risk of distrust as a third organizational constraint.

For each case of deception, I would like to emphasize that there will be a minimal risk of distrust. However, in order for the category to be a constraint on deception, I would argue that there ought to be a substantive risk of distrust. I want to exclude situations where there is a small chance of distrust occurring, but rather focus on those cases where the risk is greater than minimal or rather a *substantive* risk of distrust. Determining the level of distrust will ultimately be based on the judgment of the healthcare team regarding weighting the risk and harm involved.

### *Mental Capacity*

If a patient has mental capacity (the ability to understand and appreciate multiple factors regarding her treatment/placement)<sup>1</sup> then deception is morally indefensible. As described in earlier chapters, in order to have mental capacity patients must be able to understand and to appreciate the relevant information provided by health care providers.<sup>2</sup> They are able to decide what they want and do not want in their current condition, given all the appropriate information to make an informed decision.

When patients have mental capacity, deception is morally impermissible because it robs individuals of the ability to provide an informed consent or refusal, and it negatively impacts their autonomy to make decisions for themselves for reasons outlined in earlier chapters. As long as this decision is informed with the necessary information to make the decision, and a patient is able to understand and appreciate all necessary information, then a patient's autonomous choice should be respected. I described earlier the legal constraint on decision-making of informed consent and the legal requirement of healthcare providers to obtain an informed consent if a patient has mental capacity for that treatment. Hence, mental capacity is not only an ethical constraint given its relationship with respecting autonomy, but also a legal constraint due to legislative requirements to obtain informed consent from a person who has mental capacity. Deception would be in direct opposition to informed consent of mentally capable patients for these reasons and, is thus, an organizational constraint.

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1. *Health Care Consent Act*.

2. The detailed information required to obtain an "informed" consent is outlined in the *Health Care Consent Act* (Ibid.).

### *Compliance with Treatment (when applicable)*

Another constraint on deception occurs if a patient is compliant with taking her medication and/or with her treatment and the medication/treatment is determined to be in the patient's best interests, including her values, wishes and beliefs. When considering the risks and harms associated with deception, if the act can be avoided through a less intrusive means, then deception ought not be used. This constraint also addresses the character (referring back to virtue ethics) of a caregiver – the less often a caregiver deceives, the better it is for her character.

Hence, one must only allow for deception in cases where a patient is not taking the medication or adhering to treatment on her own. However, as described earlier, it is important to discover why the patient is choosing not to take the medication and address any concerns relating to the administering of the medication prior to considering deception.<sup>3</sup>

### *Substantive Risk of Distrust*

If the act of deception is likely to create substantive distrust, then deception ought not be used in these cases. Let us consider the types of cases for which this would be applicable.

It is important to ascertain information about a patient's previous experiences and expectations about her healthcare. In Chapter One, I discussed in great detail the role of expectations in trust, and how expectations are developed from patients' former experiences and their understanding of healthcare. It may be difficult to determine whether a patient would have a particular expected reaction to deception and especially to disclosure if the caregivers do not have a long-standing relationship with the patient. This constraint is necessary for those

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3. Sheffield Care Homes (NHS Foundation Trust), "Good Practice Guidance on Covert Administration of Medication."

patients where there is already a significant distrust in the system and in those cases where the healthcare team believes that there is future significant risk of distrust from using deception as a treatment or other means.

Substantive risk of distrust is an organizational constraint because it profoundly impacts the caregiver-patient relationship. It makes it more difficult for patients to seek future healthcare services either from the specific caregiver or from healthcare institutions more broadly. This limits a patient's future ability to exercise autonomy, as her health declines and she may not seek appropriate medical care in subsequent events. Deception could likely create significant harm to patients with a high risk of distrust as future healthcare conditions arise. Substantive risk of distrust further isolates and stigmatizes vulnerable populations, which in effect impacts access to healthcare, a concern for social justice.

Gilson writes: "At a micro-level, trust benefits people by establishing stable relationships; indeed, without trust successful relationships are almost impossible."<sup>4</sup> Mohseni and Lindstrom further discuss the importance of *social capital*. Social capital can be defined as: "those features of social structures – such as levels of interpersonal trust, norms of reciprocity and mutual aid – which constitute resources which may facilitate interaction between individuals and groups of individuals to achieve collective action."<sup>5</sup> The authors provide several significant consequences of distrust, which include unwillingness to return for future care, reluctance to use additional services and non-compliance with treatments.<sup>6</sup> Mohseni and Lindstrom completed a survey in 2004 with residents in the Sweden city of

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4. Gilson, "Trust and the Development of Health Care as a Social Institution," 1458.

5. Mohabbat Mohseni and Martin Lindstrom, "Social Capital, Trust in the Health-Care System and Self-Rated Health: The Role of Access to Health Care in a Population-Based Study," *Social Science & Medicine* 64, no. 7 (April 2007): 4.

6. *Ibid.*, 6.

Scania. Several factors were assessed for 27,963 participants.<sup>7</sup> “The results of this study indicate that individuals with low institutional trust in the health care system to a significantly higher extent have poor self-perceived health... If a person has trust in the health care system that person is more likely to seek help and receive adequate treatment.”<sup>8</sup> Hence, when there is a perceived substantive risk of distrust, the negative impacts on autonomy, trust, non-maleficence and other moral considerations can be so severe compared to any benefit that one ought to not deceive. Establishing a trusting relationship is important in the comprehensive holistic consideration of a patient’s care, rather than focusing on an immediate relief of symptoms, for example. The risk of harm associated with significant distrust and the patient not receiving future healthcare is so high that when weighing between benefit and harm, the harm would most almost certainly trump any benefit.

It is important to note, perhaps, the difference between healthcare provider employed by a healthcare institution and caregivers more broadly, such as family members and friends in the community. On the one hand, caregivers often have a well-established relationship with patients and have a stronger foundation for trust. In the previously mentioned Stroup, Swartz, and Appelbaum research study, patients were upset that family members deceived them, but this did not significantly impact their relationship.<sup>9</sup> On the other hand, healthcare providers often see patients for a small portion of their lives and cannot rely on a long-standing relationship to buffer the risk of distrust caused by the use of deception. I argue that it would be more acceptable for those who have strong trusting relationships to deceive than those who do not have an established trusting relationship. I will also note that those caregivers who have

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7. Ibid., 9.

8. Ibid., 12–13.

9. Stroup, Swartz, and Appelbaum, “Concealed Medicines for People with Schizophrenia,” 537–542.

long-standing relationships with someone in the community – consider a mother/adult child relationship – are much more prone to burnout from caring for another person over a long duration of time, whereas in-patient healthcare providers again only often see patients for a shorter duration of time. Nonetheless, some healthcare providers do have long-standing relationships with some patients, and perhaps more so that the patient’s family or friends depending on the situation. Hence, there is a need to understand the relationship of each patient with her caregiver(s).

Consider, for example, a patient who has severe paranoia and who is already very hesitant to receive treatment from the healthcare organization given her distorted experiences of reality and her feelings of paranoia. Deception in this case could be morally impermissible if there is not an established relationship with the patient. Often with psychiatric medication, as well, patients need to continue to take the medication for a very long time, which requires that patients develop a trusting relationship with their caregiver to have medication modifications and adjustments.<sup>10</sup>

On the other hand, a healthcare team may encounter a situation where there is a strong trust relationship already forged with the team. For example, consider a patient who often trusts that what the healthcare team decides is in her best interests. In this kind of case, deception would likely be morally permissible. However, one ought to use the clinical framework to determine whether deception is defensible in each specific case as there may be other reasons to not use deception for a specific patient.

I have already discussed in detail the different interpretations of trust. From an organizational/policy level it is hard to determine what expectations society and a particular

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10. National Institute of Mental Health, “Mental Health Medications.”



community expects of the healthcare organization given that the community members are so diverse. In general, truth-telling and reliability are important values and expectations of healthcare organizations and they should be fostered unless there would be significant benefit compared to harm for using deception, and there exists no other alternative with similar merits. Hence, if the deception were likely to cause substantial risk of distrust, then deception is morally indefensible. As I've argued earlier, the risk of distrust is often dependent on the kind of relationship a patient has with a caregiver and whether other forms of trust (aside from truth-telling) have been and can be significantly fostered over time.

To conclude, there are three significant organizational constraints on the use of deception in caregiving – mental capacity, compliance with treatment (when applicable) and a substantial risk of distrust.

### **Necessary Conditions**

Necessary conditions are conditions that must be first met such that deception is considered morally permissible. They do not, by themselves, make deception morally defensible. Once these factors are explored, the clinical patient-centered clinical process (which I will describe in detail later in this chapter) determines whether deception ought to be used in each unique case. The three necessary conditions that I will discuss in this section are: significant chance of benefit, disclosure (if possible) and controlled environments.

#### *Significant Chance of Benefit*

A necessary condition for the permissibility of deception is the likelihood of benefit for each patient. This condition focuses on the best interests of the patient and her prognosis, for example, from taking the medication provided through deception. I see there being two broad categories of benefits for patients – recovery and sustainable. *Recovery benefits* are those

where a patient can make a relatively quick recovery and is not likely to relapse. *Sustainable benefits* are those associated with a chronic condition, for which restoration of full autonomy is unlikely and the patient's current condition needs to be maintained as opposed to cured. Both recovery and sustainable benefits are closely related to beneficence and social justice and the various capabilities and opportunities that can be made available through taking covert medication or following a false belief. However, I want to emphasize that, essentially, deception in all its forms can be so damaging that there must be good reasons for its use (e.g. significant benefits).

Consider, for example, a patient who has a very small chance of the proposed medication being effective. In this kind of case, the use of deception would likely be morally impermissible, as the risk of distrust and its associated harms could outweigh any kind of minimal benefits from the medication. Considering proportionality, the benefits would likely not outweigh the risks and concerns of deception. Since the therapeutic alliance and trust between a patient and caregiver are so incredibly important, the benefits of the deception must be significant when weighing and balancing the associated harms and risks.

Another case may involve a patient who would either moderately or significantly benefit from the medication – for example, the medication would likely restore autonomy for the patient and she could continue to flourish and participate actively in her pre-psychotic lifestyle. For example, a brief psychotic episode is characterized by full recovery and the lack of reoccurrence and could be a situation where deception is permissible, if other alternatives are not effective.<sup>11</sup> This is an example of a short-term or recovery benefit. In this case, the chance of psychosis occurring again is minimal and the risk of deception becoming ineffective

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11. Rashmi Nemade and Mark Dombeck, "Prognosis and Recovery Factors of Schizophrenia," *MentalHelp.net*, August 7, 2009, [http://www.mentalhelp.net/poc/view\\_doc.php?type=doc&id=8806](http://www.mentalhelp.net/poc/view_doc.php?type=doc&id=8806).

due to patient knowledge after disclosure could be minimal. Nonetheless, it is hard to determine in advance whether a psychiatric illness will respond to medication, including the correct dosage and the type of medication. Caregivers simply may not be able to know what the benefits are until after a prolonged period of time. Consider the constraint that I described earlier – the risk of substantial distrust – and the importance of relationships and trust if considering using deception. Since it is difficult to determine in advance whether medication will be successful, and often in these cases no substantial relationship with the patient has been established, deception is likely indefensible. For these short-term interactions, a likely alternative would be to use coercive means if an incapable patient refuses medication, such as providing the option to either take the medication or to receive it forcibly. However, if over a period of time it is determined that a sustainable approach is needed, then deception might be considered an alternative given the likely risk/ benefit ratio.

Consider a different example that involves long-term benefit. For example, consider the case of a patient who has advanced dementia, with no hope of recovery. In this case, the patient is similar to a chronic patient in the sense that she would continuously and repetitively have cognitive episodes. One difference is, however, a patient with advanced dementia would continuously decline. In these kinds of cases, one must also consider whether there is a substantive risk of distrust, which may override using deception. Even though the patient is not recovering, her condition can be maintained through deception, as long as the benefits of its use outweigh any small risk of distrust or harm. This must be continuously assessed.

Let us further consider those patients for whom there is little chance of recovery, but for whom the illness/disease is chronic or progressive. Patients who have Alzheimer's disease, for example, where the illness progressively causes cognitive decline, fall into this category. In

these kinds of cases, patients often decline rapidly. The need for deceptively providing medications and using deception in conversation (such as deceiving that a deceased spouse is alive) will likely increase as the disease progresses. Additionally, the ability to even hold any belief significantly decreases over time with diseases such as Alzheimer's. Hence, there is a threshold when the risk of distrust is no longer a constraint on deception – when the disease process is so evolved that concerns regarding accessing future treatment and creating distrust no longer apply due to the severe cognitive decline of these patients. Hence, the reasons why deception is considered wrong, would eventually no longer apply in these situations. Nonetheless, if any other constraint is present, the act of deception is morally impermissible.

Other illnesses such as schizophrenia, however, are often life-long illnesses, with a significant chance of an act of deception leading to distrust and other harmful consequences. It is estimated that about 50% of patients who experience schizophrenia will be independent over the course of ten years; however, much of their recovery depends on how early it is diagnosed. The remainder of the patient population with schizophrenia, however, will require continuous support and intervention throughout their lives.<sup>12</sup> In cases where the illness is chronic, but not producing a rapid decline, the risk of distrust is much more significant and may place moral limits on the use of deception. In these cases, the use of deception ought to be used sparingly and extremely cautiously with patients for safety concerns, such as drug interactions and future resistance to taking medication if the patient starts to feel better. This patient population is not necessarily declining due to illness, but is often sustained, and can continue to hold beliefs for many years unlike the advanced Alzheimer's population. I will further discuss being in a controlled environment as an important condition in the next section.

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12. Ibid.

It is important to note that for medication used for mental illness, it is often a difficult process to predict and to determine which medication works best and at what dose. This approach can be lengthy for chronic illness, trying to determine the most effective and appropriate dose and type of medication.<sup>13</sup> Hence, it is unlikely that deception for regular treatment of psychiatric illnesses especially in the community at least in determining the medication type and dose initially, would be an effective method and should be avoided since it practically cannot be safely monitored and tested, or applied. Nonetheless, after determining the benefits compared to the risks (and this can of course change over time) one could consider deception as an alternative.

I have also discussed in Chapter Two why it is unlikely that using deception would occur in an emergency situation, such as when a patient is aggressive and an immediate potential harm to herself and/or others. In these cases, the medication often must be given quickly without the time available to use deception. Nonetheless, given that patients often remember previous incidents of psychosis, cases of repeated attempted deception might significantly impact trust and even cause the patient to be more disturbed if deception is attempted again and the patient is suspicious of the healthcare team. Hence, it is morally impermissible in these cases to use deception, especially given that there are other more effective alternatives that actually foster trust in an emergency – such as providing the option to a patient of either taking the medication or the staff will have to physically provide it.<sup>14</sup>

Hence, as a general guiding rule for organizational policy and procedure, if the illness is likely to have little benefit, then deception is morally impermissible due to its impact on

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13. National Institute of Mental Health, “Mental Health Medications.”

14. Forcing a patient to take medication (e.g. through restraints and an injection) can only be used, however, when the physical means are present – such as a security team or a specially trained mental health team.

trust, the patient-caregiver relationship and its long-term effectiveness as a treatment conduit. The benefits must outweigh any of the possible risks and harms, which is why significant chance of benefit is a necessary condition. Given that psychiatric medication is often provided on a trial basis to determine what works best, deception should only be used after it is the dose and type of medication are established as being beneficial for the patient and the patient continues to refuse the medication. I have argued in this section that the benefit of a treatment of medication must not only be significant, but must also be established prior to being implemented deceptively, because of the extremely high stakes for the caregiver-patient trust relationship and other harms and risks associated with deception.

*Disclosure (when possible)*

It is necessary for greater trust in the healthcare system to disclose that deception was used after it has been implemented to those who may have short-term or *recovery* benefit. However, as I described above, these cases will likely be rare. Disclosure is often not possible for those patients whom require deception to sustain a chronic or progressive illness, and, in these cases, disclosure may not be necessary. However, I want to emphasize that if the patient's condition changes and the patient is able to regain mental capacity and autonomous abilities, disclosure is required. Cases that are much more difficult are those where capacity fluctuates over time with pockets of regained autonomy. In these types of cases, it would be important to discuss an advance care plan and/or creating a community treatment order to involve the patient in deciding what to do when relapse occurs in future.

It is important to disclose that deception has occurred after capacity is regained for the many reasons listed in Chapter One and Chapter Three. For example, if disclosure does not occur, patients may believe that they got better on their own. Additionally, if they continue to

take medication, they may not know why they are experiencing particular side effects and this can be a scary incident, perhaps even worsening paranoid or delusional beliefs. Another implication of non-disclosure is that patients may inadvertently experience potentially dangerous drug interactions if they are not aware that they should not be consuming alcohol or taking other medications and so forth while being on a particular anti-psychotic or other medication. Hence, it is important to disclose that deception was used in the treatment process due to the potential dangerous consequences of non-disclosure, as well as respecting patient autonomy if regained.

An exception to disclosure is, described above, related to long-term or chronic illness. In these kinds of cases, the disease/illness has progressed so far that the reasons why we would not disclose would likely no longer apply. For example, under regular circumstances, disclosure is necessary because of the severe consequences listed above. Disclosure in the case of a patient with advanced Alzheimer's disease would not likely encounter these same consequences (e.g. concerns of drug interactions and beliefs about getting better on one's own) such as in the case of deceiving a patient regarding her deceased partner. I will discuss further in the clinical-based framework, however, that not all cases involving a patient who has Alzheimer's disease grants deception being morally permissible – we ought to refine the conversation to be more patient-centered at the clinical level. Hence, disclosure is a necessary condition for short-term cases.

### *Controlled Environments*

A final necessary condition is being in a controlled environment. I do not mean that only patients who are on secure units can be justifiably deceived. Rather, any patient who can

reasonably be monitored and observed frequently is considered to be in a controlled environment.

There are several operative morally relevant factors to justify that a patient ought to be in a controlled environment in order to implement deception. First, there can be significant side effects from a medication provided, which can be frightening and worrisome for patients. Hence, side effects must be monitored very cautiously and the dose and the type of medication altered appropriately. Additionally, in a controlled environment, staff and other caregivers can also pay close attention to the other kinds of substances that the patient ingests to anticipate and to keep careful watch for any potential drug interactions. In a controlled environment, caregivers can also observe that the patient who requires the medication is ingesting the medication fully through drink or food, and not sharing this with any others.<sup>15</sup> One can understand that there are significant harms associated with other patients ingesting medications that are not appropriate for them.

The necessary condition of a controlled environment significantly reduces harms that can occur with deception. This factor aims at reducing the risks associated with deception – this idea is most closely linked to the bioethics principle of non-maleficence. By having a controlled environment, many of the concerns that I addressed in previous chapters are mitigated through careful monitoring.

In this section, I have discussed in detail several constraints and several necessary conditions at the higher, organizational or policy level of moral decision-making for cases of deception in caregiving. To summarize, the constraints include: mental capacity, compliance with treatment (when applicable) and risk of substantive distrust. The necessary conditions

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15. Anirudh Kala, “Covert Medication; The Last Option: A Case for Taking It out of the Closet and Using It Selectively,” *Indian Journal of Psychiatry* 54, no. 3 (2012): 257–265.



include: significant chance of recovery, disclosure (when possible), and controlled environments. I used the considerations and factors described in earlier chapters to weigh and balance reasons why in certain situations deception is morally indefensible – those which involve the constraints listed above. I further used the considerations and factors to argue why there are other conditions that ought to be met before proceeding to the next level – the clinical level. Essentially, I specified the boarder principles and values to cases of deception at the organizational level. The next section will focus on further specifications to respect and to consider unique individual cases and to further decide whether deception is morally defensible or indefensible through a case-by-case analysis.

In the next section, I will discuss in detail a decision-making framework that I will call embedded specified principlism (ESP) that ought to be used at the clinical decision-making level. For example, if there are no constraints present in the situation, and the consideration of deception also accords with the necessary conditions listed above, the act of deception can be considered morally permissible. However, this does not make the act of deception the morally correct course of action – one ought to work through the framework provided below to determine whether deception is morally justifiable, as there may be another more morally defensible alternative to deception.

#### *Clinical Decision-Making – Embedded Specified Principlism (ESP)*

In this section, I will discuss the clinical process for determining the moral defensibility of deception at the case patient-specific level. Such that this process is easier to follow, I have created a series of steps in the decision-making framework for caregivers to work through. I will discuss each step and what it discloses to caregivers about the morality of deceiving in caregiving.

The clinical decision-making framework is a method for weighing and balancing the factors that were described in detail in Chapter One and Chapter Three, while also taking into consideration the alternatives discussed in Chapter Two. The steps that I introduce bring together all of the morally relevant factors to be considered for deception in caregiving. I believe that this original framework for reflecting on the morality of deception in caregiving is practical, thorough and robust such that caregivers will be able to morally justify their decision to either use or not use deception in a particular case. The decision-making framework uses principlism broadly, while maintaining a very practical series of steps for caregivers to follow. I have created a series of questions to help guide caregivers through the decision of whether one ought to deceive in each unique patient's case, with the aim that any significant red flags raised through this process will guide caregivers to not use deception. Later, I will further discuss general principles used to ensure non-arbitrariness during this process.

### **Assess the Mental Capacity of the Patient for the Present Decision**

Although I have listed mental capacity above as a constraint at the organizational level, I believe it is important to reiterate that if a patient has capacity to make decisions for herself, deception is morally impermissible.

Capacity is also treatment and time specific and cannot be assessed globally.<sup>16</sup> Hence, the assessment must be regarding the specific use of deception – whether that is regarding covert medication or other forms of deception. Given that deception is also time specific, it is important to have discussions regarding deception during those moments of regained mental capacity, when possible, to respect a patient's autonomy.

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16. *Health Care Consent Act.*

### **Bring all of the Appropriate Stakeholders Together**

This step requires that any member of the healthcare team and substitute decision-maker(s) should meet to discuss whether or not to use deception. Ideally, this would involve the substitute decision-maker(s), other family members, the most responsible physician, the social worker, the pharmacist, the SLP, the primary nursing staff, the community care access care coordinator (if applicable) and any others who are directly involved in the patient's care. Of course not all of these members may be necessary, depending on the kind of deception that is being considered.

### **Consider all Reasonable Alternatives to the Use of Deception**

Consider the list of alternatives provided in the second chapter. Would either restraints, creating a contract during moments of lucidity or truth-telling be plausible alternatives to deception? Have they been attempted in the past, why or why not? Are there any other alternatives that should be considered, such as reasons why the medication is being refused? Earlier in this chapter, I discussed how, on some mental health units, patients are offered a coercive choice to either take an anti-psychotic or to be given the medication forcefully as another option. Would this be a possibility given the circumstances?

Once the reasonable alternatives have been explored and deception is still determined to be a plausible alternative given the patient's specific history and previous experiences, caregivers must consider the legal, professional and ethical factors listed below. Any other plausible alternatives are to be kept in mind throughout this process and the alternative that ultimately has the greatest benefit to harm ratio in light of all the factors below would be the most morally defensible option.

## **Perform a Legal, Professional and Ethical Analysis**

Caregivers must consider each of the following sections carefully to determine whether the kind of deception they are considering would fit within their legal and professional constraints and whether the act of deception would be morally justifiable given the morally relevant factors discussed in Chapter Three.

This process involves specification of the bioethics principles and other morally relevant factors to each unique case. All of the morally relevant factors are listed below the legal and professional constraints. These include, and are certainly not limited to, respect for autonomy, beneficence, non-maleficence, justice and trust, to name a few. These principles were thoroughly discussed in Chapter One. I further added consequentialist, deontological and virtue ethics factors to the list of ethical considerations and I discussed each morally relevant factor in comprehensive detail in Chapter Three. I will present each factor along with a series of questions to help guide the caregiver through this framework. I describe this process as *patient-centered* as it requires that caregivers determine the specific values, needs and concerns related to each unique patient and her experiences.

### *Legal and Professional Constraints*

Legal and Professional Duties and Obligations:

(a) Informed Consent (*Health Care Consent Act, 1996*)

- Right to Choose/Right to Refuse
- Informed Consent must be provided by a patient or his/her SDM

(b) Right to Personal Health Information (*Personal Health Information Protection Act of Ontario, 2004*)

- Truth-telling

### *Morally Relevant Factors*

In this section, I list the traditional bioethics principles along with several integral questions related to their specification to each unique case. As one works through each of these sections, it is important to keep in mind any alternatives described in the first step of this process. It is necessary to review, during the process, if there are any other ways to provide medication or to reduce patient suffering that are more morally justifiable without using deception. For example, when considering respect for autonomy and what a patient would actually want, it is necessary to consider all plausible alternatives in light of what the patient would want. Some of the questions are specific to deception, but most can be applied to the alternatives as well.

In this section I provide distinct questions under each morally relevant factor. The process of specification occurs at this point in the decision-making framework. Specification is “a process of reducing the indeterminate character of abstract norms and generating more specific, action-guiding content.”<sup>17</sup> Richardson further adds that specification is completed by “spelling out where, when, why, how, by what means, to whom, or by whom the action is to be done or avoided.”<sup>18</sup> Specification is supposed to add content to the general principles as applied to specific situations. In Chapter Five I will argue why specification as a sole theory to guide ethical decision-making is inadequate.

According to Beauchamp, Childress and Richardson, specification involves taking a broad, general principle, and making it into another (or more than one) principle that is an offshoot, which is smaller in scope, yet still captures the spirit of the original principle. For example, when specifying respect for autonomy, one could articulate that an advance care plan

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17. Beauchamp and Childress, *Principles of Biomedical Ethics*, 17.

18. Richardson, “Specifying, Balancing and Interpreting Bioethical Principles,” 289.

clearly states one's wishes that should be followed if possible. This specified-principle captures the spirit of respect for autonomy in a clear and tangible way, which we can use in the case of deception.

#### Traditional Principlist Factors

- Respect for autonomy
  - What are the patient's wishes, values, goals (both substantive and experiential) and would deception align with these goals?
  - What would the patient want, if capable?
  - Has the patient ever expressed verbally how she feels about her medication, its side effects, etc.?
  - Does the patient have an advance care plan regarding medication and forms of administration? Can we create one, when the patient has lucidity?
- Beneficence
  - What are the medical indications in this given case? (Consider: diagnosis, prognosis, probability of benefit of treatment/medication/deception)
  - Is this medication necessary and/or likely to significantly benefit the patient?<sup>19</sup>
  - What are in the medical best interests of the patient, given a generally shared list of aims and goals – e.g. what would a reasonable person in our society want?
- Non-maleficence
  - What are the harms associated with covert medication/lying?

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19. Mental Health Commission for Scotland, "Good Practice Guide: Covert Medication," November 2013, [http://www.mwscot.org.uk/media/140485/covert\\_medication\\_finalnov\\_13.pdf](http://www.mwscot.org.uk/media/140485/covert_medication_finalnov_13.pdf).

- Are there any pharmaceutical concerns? (e.g. potential medication interactions, medication changes when administered in a different form, such as being crushed)
- Are there any *unknowns*, given the patient's condition and/or lifestyle that could lead to harm? (e.g. does the patient frequently use other substances in the community?)
- Can the patient be easily monitored re: side-effects? Are there known side-effects of the particular medication for this patient?
- How will the caregivers disclose, if possible, that deception occurred after the medication has restored autonomy and are there any predicted harms from doing so? How can we mitigate these harms, if possible?
- Who will be providing the medication to the patient?<sup>20</sup> Is any additional training necessary?
- Does any team member have additional concerns with the use of deception? Please describe.<sup>21</sup>
- Are the harms proportionate to the benefits? What reasons can we offer for this?
- Social justice
  - Is this patient a part of a particularly *vulnerable*<sup>22</sup>, under-represented population? How can we ensure the patient has adequate representation?

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20. Ibid.

21. Ibid., 7.

22. If the patient belongs to a more vulnerable population, especially if she does not have strong representation, then caregivers have a stronger duty to advocate for this patient population. As described above too, it is important to reduce stigma of these populations and promote the dignity of each patient.

- How can we maximize the opportunities and capabilities available for the patient given his/her values? (e.g. basic human needs, such as attaining food, shelter, companionship, other relationships, etc.)
- Fostering Trust
  - How can we foster trust better with the patient?
  - What are the patient's expectations of the healthcare system?
  - Are there any reasons we have that the patient may be more susceptible for distrust?

#### Deontological Factors

- Human dignity
  - How can we try to treat and to respect the patient as a person with intrinsic value and worth?
  - What are the patient's personal standards and how can we best ensure these standards are being upheld?
- (Set Aside: Intrinsic Value of Truth & Universality)

#### Consequentialist Factors

- Pressures on healthcare providers & non-healthcare providers
  - What are some avenues that healthcare providers can use to address resource concerns that would not jeopardize patient care?
  - Are there currently any programs that offer respite for healthcare providers and other caregivers to lessen caregiver burnout?



## Virtue Ethics Factors

- Character building (especially compassion and truth-telling)
  - What are the reasons for considering deception? Are they in keeping with the kind or type of caregiver the patient would want or, in society more generally, what a reasonable person would expect from a caregiver?

I should make a brief note here to describe why I have used distinct categories for each of the deontological, consequentialist and virtue ethics factors, as opposed to reducing them to other principlist considerations. I do not believe that Beauchamp and Childress capture these equally important considerations in their traditional biomedical ethics principles. Concepts such as human dignity and character of the caregiver are addressed but not with the same significance as the traditional bioethics principles. Beauchamp and Childress do discuss the moral personality traits associated with a caregiver, but when considering a tool for caregivers to assist with decision-making, I believe including these morally relevant factors alongside the traditional principlist moral factors is necessary for a robust and practical framework. They are also important considerations for caregivers, which make the framework more accessible to everyday ethics. I will argue in further detail in Chapter Five for some important revisions to Beauchamp and Childress' biomedical ethics principles.

After carefully specifying these factors to each unique patient's circumstances and into smaller principles, when possible, the healthcare team ought to consider together whether deception is morally permissible in the specific case presented through weighing and balancing these factors together in light of the alternatives. But how does one actually *weigh* and *balance* the information provided above?

First, Beauchamp and Childress describe specification as making general principles, such as respect for autonomy, relevant to the specific situation through more principles that are smaller in scope. For example, above, I specified respect for autonomy by asking a series of questions that relate autonomy directly to the use of deception in healthcare. Once we have responses to all of the questions and make smaller principles when possible, it is important to assign the principle a metaphorical “weight.” A weight is not a numerical value, such as in a utilitarian calculus. It is decided through judgment for each case and reflects the approximate value of each specified principle. For example, how important is the patient’s autonomy in this specific case relative to the harms that could come from deception? In one case, the harms may be significant to the patient as well as the community and would, relative to autonomy, outweigh the principle of respect for autonomy. In another case, the harms might not be significant, and autonomy might have a heavier associated weight.

Once each specified principle is considered, one needs to explore which alternative the principle is supporting – for example, is it leaning towards the use of deception or not? After placing each principle with the decision to either deceive or not to deceive, and noting that some principles can be placed in the middle, since they are not clearly either in favour of deception or not, one can determine the most morally defensible decision. The alternative that has the greatest overall support is the most morally defensible position. Note that I am not arguing that more principles that favour a particular alternative indicates that it is the right course of action. Instead, an alternative with fewer principles may be the morally defensible course of action if the overall balance of each specified principle is greater than the sum of more principles,. Additionally, it may be the case that the overall balance reveals that both alternative are morally defensible. In Chapter Five I will address how one ought to weigh and

balance factors in the most unbiased way possible – I will discuss several methods for making the weighing and balancing process as non-arbitrary as possible.

When weighing and balancing competing principles, there are several different types of cases that I describe. First, if a patient is mentally capable of making the decision for herself, then there are several main considerations (in addition to the other morally relevant factors) that ought to be weighed and balanced, which include respect for autonomy, encompassing promoting a patient's autonomy, harm to others and fairness to others when resources are limited. In the majority of cases, respect for autonomy would be weighted so strongly that the decision would be in accordance with the patient's autonomous wishes.<sup>23</sup> If, however, there may be harms to others and/or the healthcare or other resources are indeed scarce, then autonomy may be trumped by another (or other) competing principle(s).<sup>24</sup>

The cases that I focus on, however, are those where a patient no longer has mental capacity and a SDM is called upon to assist with the decision to use deception. There are three main types of cases that this would apply to, broadly conceived as: patients who are not likely to recover (but rather be stabilized consistently), patients who are declining due to disease progression (Alzheimer's disease) and patients who are likely to regain mental capacity but who may have moments of regression.

Let us explore how weighing and balancing may contribute to the decision to use deception in each of these types of cases. For each case, the procedure listed above should be followed, including exploring the list of morally relevant factors. Weighing and balancing

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23. There is also a legal requirement in Ontario and many other jurisdictions to obtain an informed consent, which would otherwise constitute battery and assault.

24. An example of this might include 24/7 individualized care in a hospital setting. Although it could potentially significantly promote a patient's autonomy, given limited resources and the duty to provide care to other patients, this is likely not feasible.

these factors is similar to determining the risks and benefits (based on each morally relevant factor) and ultimately making explicit which alternative is most morally defensible.

Principlism, however, not only considers the consequences of each alternative, but also the intentions of the caregiver as well as the value of dignity to patients (as listed in the decision procedure and discussed in previous chapters). Consider the example of a caregiver's character and the type of caregiver she should aim to be. From a consequentialist perspective, we would want to minimize future morally unjustified acts of deception especially if the act of deception makes a caregiver more inclined to deceive in other unjustified cases. However, the intentions of a caregiver to be trustworthy, honest and truthful are important considerations too. They create the kind of healthcare system that people generally value and are often what draws caregivers to caregiving and healthcare roles.<sup>25</sup> Principlism, and especially ESP, is inclusive of both the intentions and value of dignity (as described in earlier chapters) as well as the list of potential consequences of each alternative to various stakeholders, expanding beyond traditional consequentialist considerations.

Let us return to the examples listed above for incapable patients. I will discuss them briefly with a few broad examples. For the first example, which includes those patients who require sustained intervention/ medication, the principlist position would place an emphasis on the patient's autonomous wishes (if known and informed), but would also consider the patient's well-being from a beneficent viewpoint, harm to others and to the patient herself, and so forth. The previous autonomous wishes may be overridden based on the current state of the patient in addition to the other factors listed and their intensity in the specific case. An example of this situation could involve a patient who formerly expressed the desire to take a medication

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25. M. E. Miers, "Career Choices in Health Care: Is Nursing a Special Case? A Content Analysis of Survey Data," *International Journal of Nursing Studies* 44, no. 7 (n.d.): 1196–1209.

when capable, even covertly if necessary. As the patient's condition worsens and becomes a chronic illness, she becomes incapable. She is evicted from her former apartment and is now living in a neighbourhood where she participates in occasional illegal drug consumption that could interact negatively with the medication. Her circumstances have changed such that it would be harmful for her to take the medication, especially if given covertly. Monitoring the use of covert medication could no longer be possible in her current circumstances. Although she is not thriving, as she would be on the medication, she seems to have an acceptable quality of life given her new circumstances. Hence, weighing and balancing could involve overriding previous autonomous wishes for the reasons listed above.

The second kind of case involves a patient with Alzheimer's disease and she frequently asks after her deceased child, for example. Disclosing the truth depends on the circumstances of the case. Taking into consideration all of the morally relevant factors includes considering what the patient's values were prior to becoming incapable (the autonomous wishes) as well as the experiential or current incapable wishes of the patient in her current state, as examples of specified factors. Often, many people do not have wishes already established in advance about this kind of issue, however caregivers can try to have a greater understanding of the overall values a person espoused. Most people would generally want to know if their loved one deceased, however, whether or not this is disclosed when incapable will depend on previous wishes and values and the patient's overall current experience, including quality of life. Consider for example, a patient could receive the information about the death if it involves a deeply held value (such as the patient holds strong religious values that she must pray for her son to provide him blessings in the afterlife), if even it may decrease her overall current quality of life. In a different case however, if the value isn't as strongly held and quality of life is

deeply impacted, then it could be morally defensible to deceive the patient. Hence, the weighing and balancing of morally relevant factors will most often depend on each patient's unique narrative and incapable experiences.

For the last kind of case, where a patient is likely to regain autonomy but may have a relapse, weighing and balancing are also important. Again, all factors should be considered for each unique case. In some cases, the act of deception could so profoundly impact the caregiver-patient relationship that a different alternative should be considered. Consider a patient who has a strong history of paranoia and even though she regains autonomy after receiving medication, she will sometimes lapse again and have some recollection of being misled in the hospital environment so as not to return to the hospital for future concerns. The decision to deceive will take into consideration the harms associated with not returning for future treatment for other kinds of health issues – this may negatively impact the patient and others involved in the patient's life. Alternatively, the patient may continue to return for future healthcare, but also be deeply dissatisfied with the service and future services given the damaged trust relationship. Although there are no tangible harms to the patient or her autonomy for future healthcare, there has been an affront to the patient's dignity and feeling of worth.<sup>26</sup> For a different kind of case where this kind of history with paranoia does not exist and a patient has a good rapport with the healthcare team, concerns related to returning for future care may not be weighted as heavily, which could influence the decision to deceive.

The kinds of case examples I present above are very brief sketches, and actual cases are much more complex with multiple factors involved. Ultimately, the decision to deceive will rest on the metaphorical value of each factor in each case and which alternative they support.

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26. Hence, there could be a mix of utilitarian and deontological or other impacts from the act of deception, which is why I think the inclusivity of principlist account is most feasible.

Although autonomy (previously known wishes and values) is an important factor for incapable patients, there may be other factors in the current state of the incapable patient's life experience that will influence which alternative is most morally defensible.

### **Continuous Revisiting the Use of Deception**

Once it has been decided that deception is morally defensible through the ESP clinical decision-making procedure, it is important to continue to monitor and address the use of deception. It is useful to consider an analogous case of the use of restraints and the process for continuously monitoring restraints, since it is *prima facie* undesirable to use restraints, but may be necessary in rare situations.

From an organizational level, it is always important to review policies in light of new evidence-based practices and standards that are adopted across the globe. Hence, as technology and medical practices evolve, the use of deception may need further thought given other plausible alternatives in healthcare.

At a clinical level, once the decision to implement deception has been made, it is important to constantly revisit this decision in order to determine whether it is morally acceptable to continue its use. These on-going considerations include: clear documentation, careful monitoring of side effects, frequent reflection on the need for deception and disclosure. I have already discussed the importance of disclosure, when possible, earlier in this chapter, as well as the need to very closely monitor side effects, most notably in a controlled environment. I will briefly discuss the need to document deception, in addition to constant revisiting the need for its use.

Documentation is essential. If the process described in this chapter has been carefully followed, then staff can feel justified in coming to the decision to use deception. This decision needs to be documented, as it is part of the care plan for the patient and requires that all staff is aware of the plan to ensure consistency, transparency and accountability in the chart and throughout the patient's experience. If one staff member or caregiver uses deception and others do not, then this may defeat the purpose of deception if the patient prematurely discovers that this is occurring, not to mention causing significant distrust of that team member and ultimately the full team. Documentation should also include justification for the use of deception as well as how and the frequency with which it is being monitored, given the particular patient's situation and the length of time required to regain capacity and so forth. For cases when deception is used where patients will not regain capacity (e.g. for a patient who has advanced dementia), the frequency of revisiting the use of deception would be much less than for someone who is taking antipsychotic medication, for example.

The analogous cases of the use of restraints requires that staff check-in with the patient almost every hour and review the use of restraints every 24-48 hours to ensure that the least restrictive method of treatment is being provided and that the safety of the patient is guaranteed.<sup>27</sup> Constantly revisiting the use of deception ensures that staff is fully aware that its use is only temporary and that deception as a conduit for treatment is not common practice, but rather only used in extreme situations – similar to the use of restraints in healthcare.

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27. For an excellent example of a least restraints policy see, Centre for Addiction and Mental Health, "Emergency Use of Chemical Restraint, Seclusion, and Mechanical Restraint," 2009, [http://www.mountsinai.on.ca/care/psych/on-call-resources/on-call-resources/emergency\\_use\\_of\\_restraint\\_policy\\_final\\_may\\_21\\_09.doc](http://www.mountsinai.on.ca/care/psych/on-call-resources/on-call-resources/emergency_use_of_restraint_policy_final_may_21_09.doc).



## Conclusions

In this chapter, I provided further contributions to the issue of deception in healthcare. First, I discussed an organizational framework through listing several key conditions within a policy that one could adopt to justify when deception is morally defensible or indefensible. I introduced novel distinctions of constraints and necessary conditions on the use of deception. Constraints place limitations on the use of deception. Included as constraints are: mental capacity, compliance with treatment (when applicable) and risk of substantive distrust. Necessary conditions are those that are required in order to use deception. Included as necessary conditions are: significant chance of recovery, disclosure (when possible) and controlled environments. The second contribution I made in section two is a clinical decision-making process for specific cases where deception is being considered as a morally justifiable treatment conduit. I called this clinical framework embedded specified principlism (ESP). I listed all of the morally relevant factors including traditional principlism and other important ethical considerations, as well as professional and legal duties and obligations. The morally relevant factors are discussed in detail in both Chapter One and Chapter Three, and are provided in the decision-making procedure with relevant questions to help guide caregivers assess the moral justification and practicality of the use of deception in caregiving.

In the final section of this chapter, I discussed further reflections on the use of deception once the decision has been made to implement deception as the treatment conduit. These considerations include: clear documentation, careful monitoring of side effects, frequent reflection on the need for deception and disclosure. It is important to note that if the organization or caregiver has access to a clinical ethicist or other ethics related service, one should contact this individual or service for help through this decision-making procedure.

In the proceeding four chapters, I have established a comprehensive account to help guide the decision for when deception ought and ought not be used in caregiving. In Chapter Five, I will provide a theoretical defense of my modified version of specified principlism (ESP) as an additional contribution more broadly to bioethics, which stems from my analysis of the issue of deception in caregiving.

## **Chapter 5**

### **A Consideration of Methodological Objections**

I will first discuss the importance of this chapter with regards to my general thesis project – why have I chosen specified principlism as my underlying methodological approach? I will then discuss three objections to specified principlism and will respond to each in light of the embedded specified principlism (ESP) I presented in the Chapter Four. The objections are related to the following issues: non-arbitrariness, systematicity and casuistry. Lastly, I will conclude with a summary as to why I believe that ESP is appropriate in this context, and I will provide some ways in which we can further enhance and modify specified principlism (SP) based on my thesis analysis.

### **Chapter Relevance to Thesis Project**

This chapter situates my thesis argument within the broader bioethics literature. Despite modifying the principles that Beauchamp and Childress espouse, I nonetheless use the model of specified principlism and weighing and balancing of these principles to provide a moral framework for the use of deception in caregiving.

In Chapter One I described the dilemma caused by deception in caregiving as being one that can be framed in terms of competing traditional bioethics principles. Not only are the traditional ways of describing the problem relevant – autonomy versus beneficence and trust versus beneficence – but there are multiple principles and values that ought to be weighed and balanced when determining: “what ought I do?” I will argue that is useful in the context of my thesis to use principles to articulate and name what caregivers struggle with.

I will be defending the method embedded-SP (ESP). In Chapter Four, I offered a framework within which specified principlism can be applied. ESP uses specified principlism within the context of a decision procedure that I created specifically for cases of deception. I described ESP in detail in Chapter Four. Throughout this chapter, I will discuss further criticisms of standard SP and how they can be used to enhance and modify ESP even further to create a comprehensive moral framework.

There are other methods used in bioethics to explore this issue, but through providing objections and modifications I will argue that ESP is the most comprehensive and practical method for considering the issue of deception in caregiving. Other methods, such as narrative bioethics and feminist bioethics are useful and provide significant value, but I will argue that they can and ought to be used within ESP. On their own, they are not adequate as action-guiding and practical methods.

First, I will describe narrative bioethics and its potential role within ESP. Dubiel writes that Katrin Bentele first coined the term *narrative bioethics* in 2007.<sup>1</sup> Her dissertation is based on narratives and the stories of patients who had Parkinson's disease. Dubiel explores the need for narration in bioethics, as he argues that traditional principlism does not supply bioethicists and others with a concrete situated understanding of issues. The principles are too abstract, according to the field of narrative bioethics. Dubiel writes: "We have to keep in our mind, however, that the project of a narrative bioethics is not in competition with traditional forms of ethical justification. The necessity of an alternative ethical concept results from the blind spots

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1. Katrin Bentele, *Ethische Aspekte Der Regenerativen Medizin. Das Beispiel Morbus Parkinson* (Berlin: LIT Verlag, 2007). As cited in Helmut Dubiel, "What Is 'Narrative Bioethics,'" *Frontiers in Integrative Neuroscience*. 5, no. 10 (May 4, 2011): 1–2.

of an ethics based on principles alone.”<sup>2</sup> Narrative ethics aims to fill some of these blind spots.<sup>3</sup> Dubiel adds: “Biography is a strange genre, because its constitutive features – the beginning and the end of a life – are concealed to the respective person.”<sup>4</sup> It is this biography of each unique person that aims to inform the principles during specification. I think that this concept helps to respond to several of the questions that I pose in Chapter Four regarding a specific patient’s values, wishes, beliefs. Additionally, the way in which we describe harm or benefit for each patient is informed by that patient’s experiences and surroundings, essentially – her narrative. Even our specification of social justice is partially contingent on the vulnerability and capabilities of each unique patient. For example, having a history of trauma may result in a significant vulnerability regarding the use of restraints. Hence, I believe that narrative and fully understanding the patient perspective and story is necessary in order to specify principles. Narrative bioethics can be and should be incorporated directly into ESP. I do not argue that we ought to be completely subjective in deciding what one ought to do. I believe that each situation is extremely complex and that to determine the weights accorded to each specified principles requires examining the narrative and unique circumstances and history of each patient.<sup>5</sup> I will respond to the objection of arbitrariness in this process later in this chapter.

A second major method that is often discussed in bioethics is feminist bioethics. Feminist bioethics is an extremely important discipline in bioethics. Feminist bioethics has a

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2. Dubiel, “What Is ‘Narrative Bioethics,’” 1–2.

3. Another interpretation of narrative ethics is a more extreme position. For example, Jonathon Dancy argues that narrative ethics is about relying on the general feelings of the situation, as opposed to referring to or filling in the general bioethics principles. See Jonathan Dancy, *Ethics Without Principles*, 1 (Oxford: Oxford University Press, 2004).

4. Dubiel, “What Is ‘Narrative Bioethics,’” 2.

5. I do believe, however, that the organizational and policy constraints and necessary conditions provide general guidelines for when it is morally impermissible/permisible to use deception more broadly.

strong focus on issues of social justice, marginalized and vulnerable populations, as well as highlighting the importance of relationships. Autonomy need not represent the traditionally exclusive individualistic and liberal concept of autonomy, but can and should also include these other kinds of concepts. This can be captured within ESP, given that discussions of autonomy can and should include important notions such as relationships and caring. The focus on trust (a modification that I have made to ESP) also stresses the importance of relationships in bioethics. I discussed autonomy and its variations in Chapter One in more detail. Trust has also been a significant focus of previous chapters and how it relates to decision-making regarding deception. Feminist bioethics is an important method, and it can and should be used with the ESP framework when exploring deception in caregiving.

Additionally, within the principles of bioethics, justice represents the consideration of the specific vulnerabilities of each patient and how they relate to weighing and balancing potential harms associated with alternatives. Hence, I believe that similar to narrative ethics, feminist bioethics can help to inform the bioethics principles through specification and highlighting the variation that can occur within each principle itself.

I will now address three methodological objections and responses regarding the following: non-arbitrariness, systematicity and casuistry. As described above, the goal of this chapter is to argue that my intentional use of Beauchamp and Childress' SP is the best methodological way of exploring the issue of deception in caregiving, with the framework that I've discussed in Chapter Four, ESP.

## **Methodological Objection 1: Arbitrariness in Weighing and Balancing**

Being as non-arbitrary as possible is invaluable in health care decision-making. Accountability and transparency regarding the decision-making process are two key foundations for building trust in the therapeutic relationship with healthcare providers and in the healthcare system more broadly. In this section, I will discuss important guidelines and considerations to use when weighing and balancing specified principles to make this process non-arbitrary. I will first consider a list of principles that Beauchamp and Childress present to reduce arbitrariness in weighing and balancing. I will then discuss Sisela Bok's test of publicity to provide a further check and balance in the decision making-process.

### *Reducing Arbitrariness*

In *The Principles of Biomedical Ethics*, Beauchamp and Childress, present several different considerations when deciding which alternative is the most morally defensible, given the range of morally relevant factors in each case. They list the following conditions to be considered when weighing and balancing factors (or as they state, "norms") and for choosing one alternative over another for treatment and care:

- (1) Good reasons can be offered to act on the overriding norm rather than on the infringed norm;
- (2) The moral objective justifying the infringement has a realistic prospect of achievement;
- (3) No morally preferable alternative actions are available;
- (4) The lowest level of infringement, commensurate with achieving the primary goal of the action, has been selected;
- (5) Any negative effects of the infringement have been minimized;

(6) All affected parties have been treated impartially.<sup>6</sup>

The focus of these conditions aims at which method will be the least intrusive in order to achieve the primary goal (which is dependent on the patient's wishes and values). They also aim to minimize risk and harms for patients and other stakeholders. These reasons consider the proportionality of the case – do the overall benefits of deception outweigh the risks, all things considered, and have we considered all possible alternatives?

Opponents to traditional principlism, such as Gert, Culver, and Clouser (2011), state that balancing endorsed by Beauchamp and Childress is not guided by any over-arching principle to help organize the factors/principles considered in deception.<sup>7</sup> In response to this criticism, another method for organizing the principles is through a general guiding meta-principle, as described by Gordon, Rauprich, and Vollmann (2009). This meta-principle is *common morality*.<sup>8</sup> I will briefly argue why this method is inadequate, and that we should use Beauchamp and Childress' guidelines to guide decision-making.

Gordon, Rauprich, and Vollmann use Beauchamp and Childress' definition of common morality, which is: "The common morality is the set of norms shared by all persons committed to morality... The common morality is applicable to all persons in all places, and we rightly judge all human conduct by its standards."<sup>9</sup> Gordon, Rauprich, and Vollmann describe:

Of course, we do not hold the view that common morality is able to provide a unique correct answer, but it can be seen as a constraining framework that, first, separates ethical from unethical answers, and secondly, indicates which ethical

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6. Beauchamp and Childress, *Principles of Biomedical Ethics*.

7. I will discuss their criticisms and alternative approach in further detail in Chapter Five.

8. John-Stewart Gordon, Oliver Rauprich, and Jochen Vollmann, "Applying the Four-Principle Approach," *Bioethics* 25, no. 6 (July 2011): 298.

9. Beauchamp and Childress, *Principles of Biomedical Ethics*, 3.



answer seems more appropriate with regard to the ideal of common morality without saying that this is the only correct available answer.<sup>10</sup>

Gordon, Rauprich, and Vollmann argue that common morality, which is what a reasonable person who is morally inclined would do in society, helps to guide these kinds of decisions. They argue that we can balance principles in this way. For example, they use the example of a woman who autonomously wishes to have life sustaining treatment withdrawn at end of life, while her physician autonomously wishes to exercise his professional judgment to keep providing the patient nutrition and hydration, while removing other life sustaining treatment. The physician's rationale is such that the patient does not ultimately die of starvation/dehydration, but rather the underlying illness.<sup>11</sup> In this case, the authors argue that it is reasonable to balance the principles such that we respect patient autonomy and the patient's wish to not receive artificial nutrition and hydration because this is what common morality would dictate; common morality would want for physicians to follow the patient's wishes and values in these kinds of cases. Hence, according to Gordon, Rauprich, and Vollmann, common morality provides a clear response to which principle we ought to follow when we have competing principles. The idea of a common morality does not take into consider each individual patient's values and wishes, but rather considers what all persons committed to morality would want.

I think Gordon, Rauprich, and Vollmann believe that we would know what rational people in society would agree upon, but I don't believe this quick *picking* of a principle based on a shared intuition is adequate. Even though one can imagine that an average person in North-American society would want X, this does not mean that it is the morally defensible

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10. Gordon, Rauprich, and Vollmann, "Applying the Four-Principle Approach," July 2011, 299.

11. Gordon, Rauprich, and Vollmann, "Applying the Four-Principle Approach," July 2011.

course of action. I think that in cases of treatment options and plans of care, we need to be sensitive to the differences in values and preferences of non-common morality persons – this is not to say that we should do everything that is wished, as there are some necessary limitations given scarce resources and legal and professional duties. Additionally, caregivers may also weigh and balance decisions differently based on their understanding of what a reasonable person in society would desire. I think it is important to focus on the process of decision-making, which includes considering all alternatives. In the example that Gordon, Rauprich, and Vollmann provide, can we consider a reduction in feeding rather than a full stop? What medications is the patient on and should we allow natural death from withholding any of these medications instead? I think that SP and my decision-process introduced in Chapter Four, provide a robust and reflective decision-making rather than focusing on a quick solution.<sup>12</sup>

I believe that their analysis of applying the bioethics principles in a systematic way, such as to reduce the principles to a meta-principle is problematic. Rather, the use of multiple meta-principles or conditions, as described by Beauchamp and Childress provide some concrete and robust guidance rather than trying to consider what morally inclined individuals of a particular society would do more generally. The conditions presented by Beauchamp and Childress is a patient-centered approach, by not limiting the decision to what an average morally inclined person would deliberate to be the right course of action. Rather, the principles provided by Beauchamp and Childress are more inclusive of differing alternatives, perspectives and values.

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12. Of course if the decision were one that ought to be made rapidly, we may not have as much time to discuss alternatives. In my experience, however, for end-of-life decisions and discussions regarding palliative care, we usually have some time to stop, pause and consider what are all alternatives and which is the most morally defensible.

In addition, Marino argues that systematicity, or reducing multiple principles to one principle, is not necessary for a non-arbitrary approach to principle pluralism.<sup>13</sup> In her article, Marino argues that what matters for non-arbitrariness is *case consistency* between morally relevant factors. This is a similar moral argument to casuistry, which argues that we ought to base our current cases on previous or precedent cases. In case consistency, there is coherence between morally relevant factors across cases under the same circumstances. Case consistency involves prioritizing, in a principled way, such that cases with similar morally relevant factors are judged the same way, and those that have morally relevant differences are judged differently. This method of coherence denies that there ought to be one overriding principle, such as claimed by Gordon, Rauprich, and Vollmann, and rather allows there to continue to be multiple competing principles.

Weighing and balancing requires a methodological way to determine what one ought to do given multiple, often competing values and principles. I believe that using the conditions provided by Beauchamp and Childress provides some guidance to make the overall decision as to what one ought to do, given all of the values and principles considered, and the alternatives provided to deception.<sup>14</sup>

### *The Publicity Test*

The second method that we can use to consider the alternatives and reduce arbitrariness when weighing and balancing the principles is the publicity test. Bok argues that the publicity test

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13. Patricia Marino, "Moral Coherence and Principle Pluralism," SSRN Scholarly Paper (Rochester, NY: Social Science Research Network, August 14, 2012), <http://papers.ssrn.com/abstract=2296907>.

14. It is important to note that ethics does not always provide absolutely clear responses – for example, Beauchamp and Childress' first condition of having *good reasons* for overriding one principle over another, can likely be interpreted in different ways. However, a plausible response is that others in the moral community, such as reasonably minded individuals, would agree upon these reasons as being good ones.

appeals to justification along similar lines to Gordon Rauprich, and Vollmann: reasonable persons would agree to the decision. Bok argues that generally, the world is better off for people telling the truth, since this fosters trust and less energy is expended on trying to figure out what is true and what is false. On this account, one is more productive in the sense that one can participate in the world with less barriers by having a trusting relationship with others: scepticism and uncertainty requires lots of energy and time.<sup>15</sup>

Bok argues for an egalitarian moral view, such that we benefit from one another by adopting a general Principle of Veracity, or truth-telling. Similar to the principle of universality articulated by Kant, lying only works if there is the possibility that others will believe the lie. Hence, if there is a general scepticism in society and people are reluctant to believe what others say, lying will at the very least be very difficult and certainly make it much harder for others to achieve their ends, including the liar. Hence, Bok argues that through a mutual contract, we agree to trust one another through truth-telling in order for everyone, including all individuals, to benefit.<sup>16</sup>

### **Procedure for the Publicity Test**

Bok does not argue that lying is wrong in *every* case. Rather, she defends the position that there may be situations when the use of a lie is justified. She discusses the analogous case for using force. Generally, we argue that using force against someone else is wrong. For example, punching another person is on most occasions considered wrong. However, if someone is

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15. Robert K. Fullinwider, "Sissela Bok on Lying and Moral Choice in Private and Public Life – an Amplification," *Infed.org*, 2007, <http://infed.org/mobi/sissela-bok-on-lying-and-moral-choice-in-private-and-public-life-an-amplification/>.

16. *Ibid.*

attacking you, one could argue that punching that person may be necessary if other alternatives either have not worked or are simply implausible given the circumstances.<sup>17</sup>

Bok uses a procedure and standard method for determining whether the lie is morally justified.<sup>18</sup> The Publicity Test asks which lies, if any, would survive the appeal for justification to reasonable persons.<sup>19</sup> Bok describes some of the advantages of publicity: “Such a test counters the self-deception and bias inherent in the liar’s perspective. It challenges privately held assumptions and hasty calculations.”<sup>20</sup> There are several questions to consider in this process, each of which are discussed by Bok:

- (1) Are there alternatives to using the lie, which are truthful?
- (2) What are the reasons and justifications presented in favor and against the lie?
- (3) How would a public jury of reasonable persons react to the lie?<sup>21</sup>

As one can see, the first condition is similar to step four in my clinical decision-making procedure – it relates to the alternatives that can be considered or attempted prior to utilizing deception as the most plausible alternative. The second question is also captured in my clinical decision-making procedure, which systematically takes caregivers through a step-by-step process of exploring each of the morally relevant factors – the reasons and justifications in

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17. Ibid., 41.

18. Ibid., 91.

19. Other philosophers writing on bioethics issues similarly discuss the publicity test, including Gert, Culver, and Clouser (Gert, Culver, and Clouser, *Bioethics*; Danner Clouser and Bernard Gert, “Concerning Principlism and Its Defenders: Reply to Beauchamp and Veatch,” in *Building Bioethics*, ed. Loretta M. Kopelman [Dordrecht: Kluwer Academic Publishers, 1999]). For these authors, impartial, rational agents estimate the harms of both proceeding with the moral rule violation and not proceeding with it, if the violation were publicly known. If every rational person agrees that the harms are less by proceeding with the violation, then the violation is deemed morally obligatory. I will discuss Gert, Culver, and Clouser’s moral approach and defend Beauchamp and Childress’ principlism in the final chapter.

20. Fullinwider, “Sissela Bok on Lying and Moral Choice in Private and Public Life – an Amplification,” 92.

21. Ibid., 90–106.

favour and against the act of deception. Lastly, the third question takes into account conditions one and two, and analyzes what a public jury would say about the decision to deceive or to not deceive, given the particular circumstances and specifications of the case.

Bok argues that most lies would fail the publicity test and that we could plausibly find other truthful alternatives for the dilemma. However, she does provide the moral space to consider and, in some cases to allow, justified deception. Not only is it important to introspectively consider these questions and to perform a hypothetical publicity test, but also Bok discusses the importance of discussing the dilemmas with peers and others in order to obtain an inter-subjective approach to resolving the dilemma. With greater perspectives around the table, one can often consider more alternatives and provide greater insights into issues, including challenging personal biases. In deception in healthcare situations, one could plausibly bring the relevant members of the team to the table to discuss options and the various morally relevant factors for each unique case. Hence, both the guidelines proposed by Beauchamp and Childress and the publicity test forwarded by Bok are effective ways to reduce arbitrariness in weighing and balancing specified principles.

### **Methodological Objection 2: Systematicity**

The second objection to the methodological procedure of ESP is systematicity. Systematicity supports the idea that an ethical theory is a good one if we can simplify decision-making through a unified and complete theory.<sup>22</sup> An example of systematicity would be to have the least number of steps or principles required to make a decision. Gert, Culver, and Clouser argue that the principles of bioethics can be systematized through what I will call the Moral

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22. Marino, "Moral Coherence and Principle Pluralism."

System Approach (MSA). They offer their account as a simple, practical method to resolve bioethics dilemmas, and they argue that their method is more systematic than SP. In this section of Chapter Five, I will discuss the MSA and why I believe that their version of systematicity does not make a better moral approach than my expanded framework, ESP, regarding deception in caregiving. Beauchamp and Childress further state:

Advocates of systematic theory may have aspirations of decisively settling applied questions, but they are no better positioned to do so than pluralistic accounts. Proponents of the same type of general theory commonly disagree about its commitments, how to apply it, and how to address specific issues (for which we do not fault them, given our earlier arguments that such disagreement is ineliminable).<sup>23</sup>

When we consider unified theories, such as utilitarianism, Beauchamp and Childress argue that these theories suffer from the same kinds of problems as pluralistic theories. They both require interpretation in specific situations, and in terms of the meaning of words such as harm and interests. Their pluralistic SP theory contains more principles than just harm that require interpreting and application, but Beauchamp and Childress argue that this does not necessarily mean their theory is flawed or less morally defensible than a systematic theory. Instead, they argue that pluralism more accurately represents the kinds of values and decisions that common morality is faced with and the complex factors that one ought to consider.<sup>24</sup>

Gert, Culver, and Clouser present MSA as a systematic alternative to SP in an effort to provide a clear method for attempting to resolve bioethics dilemmas. I have already described above how SP can respond to the criticism of arbitrariness with respect to weighing and balancing. In this section, I will focus on the question of systematicity. First, I will describe MSA and then I will discuss my objections to the systematicity argument.

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23. Beauchamp and Childress, *Principles of Biomedical Ethics*, 388–389.

24. *Ibid.*, 389.

The MSA is comprised of four major parts. First, there are moral ideals. These ideals are virtues or principles that we ought to strive towards. However, they are not obligatory and not acting upon a moral ideal would constitute as no moral wrongdoing. On the flip side, if one were to follow through with an ideal, it would be considered supererogatory or beyond what is morally defensible. An example of a moral ideal could be helping someone carry their shopping to the car when they seem to be struggling. This act is not a moral imperative, but rather an act that is above and beyond regular moral duties.<sup>25</sup>

Moral rules, however, are directives or principles that ought to be followed, unless a person has good reason to override the rule. The MSA rules include the following: “(1) Do not kill. (2) Do not cause pain. (3) Do not disable. (4) Do not deprive of freedom. (5) Do not deprive of pleasure. (6) Do not deceive. (7) Keep your promise. (8) Do not cheat. (9) Obey the law. (10) Do your duty.”<sup>26</sup> The moral rules are generated by appealing to reasonable morally-inclined persons in common morality. Gert, Culver, and Clouser describe these rules as being derived by an agreement between every impartial rational person.

The third component of the MSA is the morally relevant features. Similar to specification, the MSA requires that the decision-maker(s) respond to a number of questions regarding the morally relevant features of the specific situation. These can include, but are not limited to: the harms that would be caused, prevented and avoided, the relevant beliefs and desires of the people who are affected by the rule violation and what benefits would stem from the rule violation, to name a few.<sup>27</sup> It is the responses to these questions that help to decide whether or not a rule violation is morally justified, according to Gert, Culver, and Clouser.

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25. Gert, Culver, and Clouser, *Bioethics*, 43.

26. *Ibid.*, 36.

27. *Ibid.*, 39–40.



The final part of the MSA is the two-step decision-making procedure. The first step involves articulating the justification as to how the morally relevant features either support or oppose a moral rule violation. This step is important for the justification of the decision to choose one alternative (or multiple alternatives) over another. The second step of the decision-making procedure is what has been described earlier as the *publicity test*. During the second step, impartial, rational agents estimate the harms of both proceeding and not proceeding with the moral rule violation if the violation were publicly known. If every rational person agrees that the harms are less by proceeding with the violation, then the violation is deemed morally obligatory.<sup>28</sup>

Gert, Culver, and Clouser argue that these steps provide justification for the alternative chosen, as well as practicality given the publicity test and clear steps given in the process. The MSA is supposed to be a systematic alternative to SP, proving to have greater justificatory power and practicality than SP. In “Bioethics as Methodological Case Resolution: Specification, Specified Principlism and Casuistry” Anne Iltis defends these two criteria as being the main contemporary goals of bioethics. I will discuss briefly these two criteria in more detail.<sup>29</sup>

I believe that for an ethical theory to be a good one, a person should be able to explain or justify why she chooses one alternative over another. The theory that is used to help work through a challenging situation should allow a person to articulate the reasons why she chose one alternative over another, and these reasons should be convincing at least to most reasonable people. Along similar lines, an ethical theory ought not only provide a list of

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28. Clouser and Gert, “Concerning Principlism and Its Defenders,” 186.

29. Ana Smith Iltis, “Bioethics as Methodological Case Resolution: Specification, Specified Principlism and Casuistry,” *Journal of Medicine and Philosophy* 25, no. 3 (2000): 271–284.

alternatives, but the alternative chosen also should be action-guiding. Working through an ethical framework or theory to help decide why one should pick a specific alternative over another should produce a response or more that can be justified. Beauchamp and Childress discuss eight criteria for a moral theory, and these include: clarity, coherence, comprehensiveness, simplicity, explanatory power, justificatory power, output and practicability.<sup>30</sup>

An ethical theory, when being applied to a medical situation that requires action, needs to be practical. The action-guiding component must include alternatives that can tangibly be achieved or aimed towards, such that a person can actually act upon the alternative. This also includes the idea that a decision-making process must not be too cumbersome to complete, given the often-limited time and resources that caregivers have when making health care decisions.

First, let me briefly restate the decision procedure involved in SP as the following:

- (1) Specify the four principles of biomedical ethics given the particular situation;
- (2) Weigh the specified principles given the details provided via step one;
- (3) Balance the principles to determine which alternative will cohere with the greatest weighted combination of principles;<sup>31</sup>
- (4) If the principles do not align with common morality, then adjustments need to be made through reflective equilibrium.<sup>32</sup>

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30. Beauchamp and Childress, *Principles of Biomedical Ethics*, 334–335.

31. It is important to note here that to maintain non-arbitrariness, Beauchamp and Childress present six further considerations when balancing. Refer to earlier in this chapter for a discussion of these considerations.

32. This can occur either through revision of the specification of the biomedical ethics principles or through revision of views held in common morality.

Gert, Culver, and Clouser claim that principlism is: "...an unsystematic and ad hoc collection of independent principles."<sup>33</sup> Gert, Culver, and Clouser respond to principlism, which they consider to be simply a list of principles, with no guidance on how to use or to apply these principles to actual decisions.<sup>34</sup>

In what ways does the MSA claim to have stronger justificatory power and practicality than SP? I will argue that despite Gert, Culver, and Clouser arguing that there are significant differences between the MSA and SP, they share many of the same justification processes and both prove to be practical. However, I will ultimately argue that SP (when in the context of a decision-making procedure) is more practical and provides stronger justification for decision-making than MSA.

Gert, Culver, and Clouser argue that SP is merely a list of individual principles that do not provide normative or action-guiding strength. Any decision, according the authors, is made purely ad hoc with no linking or connecting between the principles. Hence, they argue that their moral system provides the link between the moral rules and morally relevant features through the two-step decision procedure.<sup>35</sup> Let me now describe the MSA decision-making process:

- (1) Identify the morally relevant features in the specific case;
- (2) Articulate the justification why the morally relevant features either support or oppose a moral rule violation;
- (3) Apply the publicity test.

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33. Gert, Culver, and Clouser, *Bioethics*, 99.

34. *Ibid.*, 100–101.

35. *Ibid.*, 103.

First, SP is not a stand-alone decision-making procedure. Beauchamp and Childress do not argue for a precise decision procedure, but rather they present a theoretical reflection of the principles that provide the foundations for bioethics decision-making.<sup>36</sup> Hence, the critique forwarded by Gert, Culver, and Clouser regarding the lack of a procedure is a straw man argument, given that this is not what they claim to be doing. Their principles are to be regarded in light of further critical steps in bioethical decision-making.

This being said, on what grounds can we compare the systematicity of the MSA and SP? I will focus on the broader comparison of the methodology that I have used in Chapter Four as embedded-SP (ESP). As described in Chapter Four and above, ESP uses specified principlism within the context of my decision procedure. I will compare ESP and the MSA in light of justificatory power and practicality for each of the decision-procedures.<sup>37</sup> I will use two main criticisms of the MSA with regards to these criteria: (1) justificatory power and (2) practicality.

#### *Justificatory Power*

My concerns with the MSA decision-making process begin with the morally relevant features of a case. Gert, Culver, and Clouser criticize Beauchamp and Childress for choosing ad hoc principles to begin the process of specification, but I believe that choosing morally relevant features is completed in a similar manner. Gert, Culver, and Clouser list a series of ten different questions related to morally relevant features of a case. These include for example, listing the harms avoided, prevented or caused by violating a moral rule violation, the beliefs

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36. Beauchamp and Childress, *Principles of Biomedical Ethics*, 332.

37. I also acknowledge that the MSA, based on Gert, Culver, and Clouser's criticisms of SP, and not of my newly-developed decision-procedure.

and desires of those affected by the moral rule violation and whether the rule violation is intentional.<sup>38</sup>

I believe that using a framework, such as principles, to consider the morally relevant features is actually very useful. The biomedical ethics principles describe what we often value and the umbrella of values that we ought to consider in every case. The principles of biomedical ethics help us to practically determine what we need to consider as a starting point for morally relevant features of a challenging case. From this point, we can specify them further as related to the case at hand. MSA on the other hand, requires that we address each of the morally relevant features as a starting point – the list of features they provide.

Gert, Culver, and Clouser do provide a list of different questions that one can consider regarding the morally relevant features. However, this list can be viewed in light of the principles of biomedical ethics since their goals are quite similar – the biomedical ethics principles provide a clearer understanding regarding justification to explain the reasons why we explore ethical questions. Instead of just considering the wishes and beliefs of a patient, the biomedical ethics principles elucidate that we do and should value autonomous wishes and beliefs and analyze them in light of benefits to others, reducing harms and acting upon justice.<sup>39</sup> For this point of comparison, I think that ESP is more practical than MSA. It has fewer principles, from which we can specify specific details of a case. It also frames the discussion in terms of what we value, through autonomy, non-maleficence, beneficence and social justice, as opposed to listing a variety of different unrelated questions. Considering

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38. Gert, Culver, and Clouser, *Bioethics*, 39–40.

39. Gert, Culver, and Clouser also include professional duties and legal obligations among the morally relevant features and moral rules. I will discuss concerns with this blending in the next section.

systematicity, the principles are more concise to remember, yet also very descriptive and substantive of the values we tend to hold and ought to consider.

Another criticism of the MSA relates to reducing all values to the notion of harm. Gert, Culver, and Clouser argue that the principles of biomedical ethics have some significant overlap and can all be reduced to harm. There is one unified comprehensive principle that can incorporate all of the others – do no harm. For example, Gert, Culver, and Clouser argue that beneficence can be reduced to non-maleficence. Trying to promote good or the best interests of a patient is essentially the same as trying to remove any harms for the patient, according to Gert, Culver, and Clouser. I have already discussed in detail the different principles in Chapter One, especially how I view beneficence as being distinct from respect for autonomy, as its own bioethics principle. There are those who question whether beneficence is distinct from non-maleficence and if they belong in separate categories.<sup>40</sup> In this section, however, I would like to address the important differences between non-maleficence and both respect for autonomy and justice. Can we and should we reduce these principles to non-maleficence (do no harm)?

First, respect for autonomy means engaging each unique patient to understand better her circumstances, values and wishes. This is captured as a morally relevant feature, but I find it curious that it is not considered a moral rule – to respect the autonomous wishes of patients. Respect for autonomy also requires trying to support these values and wishes as best we can in healthcare, given the limited resources and standards of practice they have developed in healthcare. Can we reduce respect for autonomy into non-maleficence or to one of the morally relevant features? Gert, Culver, and Clouser utilize harm in two ways. First, harm is broken-down into more specific examples or categories through the ten moral rules. Second, harm is

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40. Robert M. Veatch, "Resolving Conflicts Among Principles: Ranking, Balancing, and Specifying," *Kennedy Institute of Ethics Journal* 5, no. 3 (1995): 199–218.

examined through the public lens to determine whether the moral rule(s) violation is acceptable in society.

The two moral rules that Gert, Culver, and Clouser espouse which are most directly relevant to autonomy are “do not deprive of freedom” and “do not deprive of pleasure.”<sup>41</sup> The other rules are also relevant in the broader sense of autonomy since, for example, killing someone would inevitably infringe on someone’s autonomy. Nonetheless, in the traditional sense of bioethics, respect for autonomy focuses on exploring the needs of each individual patient and providing patients with the ability to refuse or accept treatment depending on their own concept of “the Good” and what matters to him or herself. “Do not deprive of freedom” is seemingly a negative interpretation of allowing someone to make decisions for herself. It involves stepping back to allow someone to have freedom to decide and act as one desires. An analogy to this same idea is thinking about negative and positive freedoms. Negative freedoms imply a freedom from interference, whereas positive freedoms imply a duty to provide the freedom.<sup>42</sup> Gert, Culver, and Clouser seem to argue that the duty caregivers have towards respect for autonomy is a negative freedom.

However, respect for autonomy in the traditional sense has a different connotation, more along the line of a positive freedom. It is a healthcare provider’s duty to support the patient’s wishes and values, including by considering creative ways to enhance autonomy. An example may include facilitating an event, such as a tea party, on a palliative care unit to fulfill a dream for a patient dying from a terminal illness. Respect for autonomy is a more patient-

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41. Gert, Culver, and Clouser, *Bioethics*, 36.

42. Ian Carter, “Positive and Negative Liberty,” ed. Edward N. Zalta, *The Stanford Encyclopedia of Philosophy*, 2012, <http://plato.stanford.edu/archives/spr2012/entries/liberty-positive-negative/>.

centered approach to actively facilitating autonomous wishes, as opposed to merely disinhibiting freedom. The same argument can be made for not depriving someone of pleasure.

First, I find Gert, Culver, and Clouser's definitions to be quite vague – they do not specify what pleasure actually means and in light of whose perspective. Does pleasure simply mean basic pleasures, like having food and being bathed or should it be interpreted more broadly to include what each patient would consider a pleasure? I think that Beauchamp and Childress' principle of respect for autonomy is a much richer and comprehensive way of thinking about patient-centered care. I am not arguing that Gert, Culver, and Clouser's moral rules can be reduced to the principle of respect for autonomy, but rather that respect for autonomy is a richer concept than the two moral rules, providing stronger justification for decisions made by healthcare providers. The moral rules stated by Gert, Culver, and Clouser also do not have as strong of a humanistic component to them, failing to explore and to prioritize the important narrative and story of each patient. The moral rules focus on prescriptive duties, as opposed to a more empathetic and patient-centered values, held deeply by healthcare providers. Hence, I have argued that we cannot reduce respect for autonomy in the form of mini-principles derived from non-maleficence.

Justice can be considered similarly. Although one might argue that many of the moral rules are related to justice – do not cheat, obey the law, etc. – this interpretation of justice is very high-level. Beauchamp and Childress, instead, argue that justice is examining more concretely those groups who are often marginalized and require additional consideration beyond the standard approach. They consider vulnerable populations, such as the elderly and those who suffer from mental illness, and explore how we can promote their wellness and well-



being in light of commonly held stigma towards these populations. Again, the richness of this idea is simply not captured in the moral principles.

### *Practicality*

Included in the list of questions that Gert, Culver, and Clouser propose, are those that aim to identify the legal aspects of a case. I believe that the decision-framework that I created in Chapter Four provides a much clearer and practical process for establishing first, the legal and professional duties of a healthcare provider – these obligations establish the parameters within which the ethical deliberation occurs. The MSA does not make this clear, and involves much ethical deliberation prior to discussion around the legal boundaries within which a healthcare provider or caregiver works.<sup>43</sup> Hence, the decision framework that I provide is more practical in determining what one legally and professionally can and cannot do prior to engaging the nuances surrounding the ethical discourse. It saves healthcare providers the time to consider what they can and cannot do, prior to discussing alternatives.

I also wish to comment on the last moral duty of “do your duty.” I find this moral rule misleading given that the other moral rules are duties for which healthcare providers ought to obey, unless they have good reason to override. Gert, Culver, and Clouser write that the moral rule “do your duty” entails a positive duty, whereas the moral rules are a negative duty, or a prohibition.<sup>44</sup> Gert, Culver, and Clouser also state that in professional contexts, some moral rules become duties.<sup>45</sup> These rules are often considered as the professional duties that healthcare providers have in association with being part of a particular college or professional

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43. The legal implications and parameters are not discussed until the 7<sup>th</sup> morally relevant feature.

44. Gert, Culver, and Clouser, *Bioethics*, 79.

45. *Ibid.*, 80.

body. I described above why it is important, practically, to determine the legal boundaries within which one must work and the same argument applies to professional duties. Sometimes the professional duties will come into conflict, as with the biomedical ethics duties (there is much overlap between them), and one must determine from these what one ought to do. However, outlining what those duties are in advance may provide more directive guidance than waiting for a discussion of rule violation, as it frames the problem and helps to elucidate constraints early on.

Beauchamp and Childress do not define duties in this way, but rather discuss duties as norms, which are prima facie binding.<sup>46</sup> The norms are defined as the specified principles used in their framework. Considering systematicity and practicality, I believe that the idea of having multiple competing duties is a more practical concept that encompasses both prohibitions as well as promoting a patient's autonomy and well-being, and avoids speaking about duties differently in different contexts.

Gert, Culver, and Clouser further defend that the moral rules can be specified for each culture and in "myriad settings."<sup>47</sup> Again, this process is closely linked to specification of principles, a concept that Gert, Culver, and Clouser criticize. In interpreting a moral rule in a specific situation, Gert, Culver, and Clouser also argue that this may not result in a moral rule violation – it is dependent on how it is specified.<sup>48</sup> They consider specification to be, again, ad hoc and to not allow SP to be more systematic in its approach. However, Beauchamp and Childress spend much time in their chapters on the four main biomedical ethics principles outlining how these general principles are interpreted in the process of specification. Gert,

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46. Beauchamp and Childress, *Principles of Biomedical Ethics*, 13–15.

47. Gert, Culver, and Clouser, *Bioethics*, 79.

48. *Ibid.*, 125.

Culver, and Clouser similarly utilize the morally relevant features as ways to tap into the specific details of each case. Hence, although Gert, Culver, and Clouser claim that their approach is more systematic through practicality, Beauchamp and Childress have the same practical benefits in SP.

In addition, when considering a practical approach to ethical decision-making, one ought to consider what would be most helpful to front-line health care provider. For example, would discussing rule violations be the best way to capture the important content of morally relevant information? Or, would discussing alternatives and then the morally relevant features in light of each of these cases be more useful? How do we foster a practical procedure, while still maintaining a comprehensive and robust decision procedure? I have argued in this section that the biomedical ethics principles espoused by Beauchamp and Childress offer a robust consideration of what matters in these cases, while not reducing important values simply to harm. I also argued that by thinking about alternatives and how the principles are operative in each is a practical approach for healthcare providers to understand and analyze what is the most morally defensible alternative.

To conclude this section, although there are those who criticize SP for not being systematic, I argued in this section that Beauchamp and Childress' account of SP provides the justificatory power that we require from a robust ethical framework. They do this by utilizing the comprehensive principles of respect for autonomy, beneficence, non-maleficence and justice rather than reducing these equally valuable concepts to a single concept, such as reducing harm. SP embedded in the clinical framework for deception (ESP) also provides a clear and practical method for determining the limitations that one has regarding legal and professional duties, in an appropriate and practical way. The order in which I integrate these

considerations frames the problem early in the decision procedure to elucidate the constraints on decision-making.

Hence, I have argued that the moral rules offered as a systematic alternative to ESP lack significant content, which fewer principles supplied by Beauchamp and Childress can actually offer. The ESP methodology hence provides greater justification due to the depth of the individual principles, and is yet still practical when embedded into a decision framework for front-line caregivers such as the one that I offer.

### **Methodological Objection 3: Casuistry**

Although there are several theories in bioethics, there are those who believe that an anti-theorist or a particularistic position is more appropriate.<sup>49</sup> ESP is a top-down method of applying general moral principles to specific cases. Casuistry is a bottom-up approach, which considers the specific circumstances first and deliberates as to what other paradigmatic cases would recommend as the morally appropriate response.<sup>50</sup> Case law would be an analogous situation to casuistry. Case law utilizes precedent cases from previous court hearings and argues based on the relevant features of the previous case, what a judge ought to decide. Casuistry utilizes the morally relevant features of each case to determine what one should do in future cases. Jonsen describes casuistry as: “rhetorical reasoning applied to moral matters.”<sup>51</sup> The stories and the experiences of the past help to inform what one ought to currently do.

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49. “SEP - Snapshot,” accessed March 2, 2015, <http://plato.stanford.edu/archives/sum2013/entries/theory-bioethics/>.

50. Albert R. Jonsen, “Casuistry: An Alternative or Complement to Principles?,” *Kennedy Institute of Ethics Journal* 5, no. 3 (September 1995): 237–251.

51. *Ibid.*, 241.

Jonsen argues that casuistry may find a moral theory useful if there is a brand new ethical issue, such as the introduction of a new life-sustaining treatment, or if there is a need to challenge an entire social institution. However, for most daily ethical dilemmas, one can rely on previously held judgments according to Jonsen.<sup>52</sup> From a moral theory perspective, Beauchamp and Childress do not deny the importance of exploring commonly held moral views of a community to determine how to specify and apply principles to concrete cases. Nonetheless, the question arises regarding methodology – what is the best method for both a practical and morally justifiable ethical framework?

In many ways, casuistry may be attractive given its reference to former paradigm cases, which have already done much of the moral work for decision-makers. Decision-makers examine what has been done in the past and utilize the morally relevant features to choose which is the most morally similar case to decide what one ought to do. Jonsen does argue that casuistry is not a distinct discipline from moral theory. He uses the analogy that when faced with a dilemma, a person ought to investigate the “palace” in which the dilemma occurs, similar to a detective, paying close attention to the specific details of the contents of room (e.g. who is involved, what happened, etc.). He states that the moral principles are like the walls of this room, framing the dilemma in terms of pillar values that we hold.<sup>53</sup> Jonsen argues that the foundational principles are complimentary to the casuistic details – one cannot function without the other. Beauchamp and Childress would not dispute this fact, as they argue that specification, or extrapolating the principles to the details of each case, is a necessary step in the ethical decision-making process.

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52. *Ibid.*, 246.

53. *Ibid.*, 241.

Carson Strong similarly argues that specified principlism on its own does not offer a non-arbitrary way of weighing and balancing competing specified principles, and that casuistry offers a practical way to do this – by observing how we have done so in the past.<sup>54</sup> However, I argued earlier in this chapter that weighing and balancing can be non-arbitrary through the use of Beauchamp and Childress’ guidelines and Bok’s publicity test. Nonetheless, I think that casuistry can be useful in exploring the appropriate weights of competing specified principles given former similar situations, but I do not believe that these are necessarily the correct responses.

Hence, I do not believe that casuistry is in conflict with principlism, but rather casuistry can be viewed as an important step in the decision procedure. Perhaps one need ask, which comes first, as with Gert, Culver, and Clouser’s MSA – the detailed analysis of the morally relevant features of a particular case and then a discussion of how they relate to the broader principles (moral rules in the MSA) or a discussion of how the principles inform a case by processing how they are applied?

I have argued in the previous section as well as in Chapter Four that from a practical standpoint, a decision-maker ought to first have in mind the alternatives of what one can do. From this position, a decision-maker should consider the principles and how they apply to the case scenario. The principles are comprehensive, given their extensive content, and they are practical in that they are simple to remember. The general principles focus decision-makers on what matters and then allows a robust discussion regarding what one ought to do. From a practical standpoint, this allows a decision-maker to identify the broadly important considerations and then narrow in on the particulars. In my opinion, this is much more useful

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54. Carson Strong, “Specified Principlism: What Is It, and Does It Really Resolve Cases Better than Casuistry?,” *Journal of Medicine and Philosophy* 25, no. 3 (2000): 334–335.

than first trying to determine the particulars and then discuss how they matter in a case. ESP is an organized, comprehensive, and practical approach that covers all of the broad moral considerations and allows the decision-maker to reflect carefully on each important category of values.

I also believe that if decision-makers wish to consider first the moral particulars of a case that is morally acceptable too. I would urge, however, decision-makers to consider the broad headings of the moral principles and other considerations that I have included in the framework to ensure that all morally relevant features of the case have been explored before deciding upon an alternative.

From this position of gathering information, casuists would inevitably explore similar or like cases to determine what one should do. How is the case similar and/or different to previous cases? In order to ensure due diligence in a particular case, I believe that this process of comparison can inform how we should assign weights to varying principles and balance them. However, I argue for a patient-centered framework such that the morally relevant features in one case may be weighted differently in another given the specific circumstances and values, beliefs and wishes of each unique patient.

I believe that it is important to consider that just because we acted in a certain way in the past, does not necessitate that this is the way that we ought to conduct present or future cases. I disagree with Jonsen's assessment that the principles of biomedical ethics are only directly or explicitly used in new cases that arise – such as with new reproductive technology, for example – and when we wish to change a social institution. I think that these principles ought to be operative in each decision, as a kind of check and balance to explicitly explain deeply held values and reasons for the chosen decision. Rather than appealing to a previous

decision, reflecting on whether the decision continues to be the right decision helps decision-makers to shape the moral landscape of biomedical ethics. This would occur if even the decisions were about particular cases and not necessarily for large innovations or institutions. I think it is important if one were to alter the moral landscape in such a way to be able to justify this decision, such as through the principles that Beauchamp and Childress suggest. This would aim to ultimately eliminate non-arbitrariness.

Ana Iltis further criticizes casuistry: “How are we to decide which cases are paradigm cases and which aspects of cases are morally relevant?”<sup>55</sup> Choosing the paradigm cases is similar to virtue ethics and choosing the paradigm example of a virtuous person. How does one know when we have chosen correctly in the past? Or perhaps we’ve been previously mistaken in our decision-making? Consider for example cases where, as a society, we have decided that current practice does not adequately reflect common values. In these types of cases, ESP would require that we apply reflective equilibrium to the principles and cases to revise one in order to be coherent. Casuistry however indicates that the right alternative is one that is based on past decisions.

Beauchamp offers a clear response to Iltis’ criticism of casuistry regarding *how* we choose which features are morally relevant ones. He states: “For a casuist to reason morally, one or more settled values must connect the cases (hence the necessity of ‘maxims’, or moral generalizations).”<sup>56</sup> The moral principles and their specifications provide the comparative points between different cases. They are generally accepted and comprehensive comparative points. Beauchamp further writes:

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55. Iltis, “Bioethics as Methodological Case Resolution,” 275.

56. Tom L. Beauchamp, “Reply to Strong on Principlism and Casuistry,” *Journal of Medicine and Philosophy* 25, no. 3 (2000): 346.



Casuists sometimes write as if cases lead to moral paradigms, analogies, or judgments entirely by their facts alone or perhaps by appeal only to the salient features of the case. But no matter how many salient facts are stacked up, we will still need some transferable *value* premises in order to reach a moral conclusion. The properties that we observe to be of moral importance in cases are picked out by the values that we have already accepted as being morally important. In short, the paradigm cases of the casuists are value-laden with general norms, and a case would not be a paradigm case without those normative commitments. To this extent, general principles do not follow from cases (even if it is also true that paradigm cases do not follow from principles)<sup>57</sup>

In summary, I believe that both Jonsen and Strong would agree that casuistry is not a stand-alone method for resolving ethical dilemmas. Despite their desire to increase practicality for ethical decision-making, I believe SP is a necessary foundation for ethical deliberation and that casuistry is one method that can be used to help weigh and balance principles. The framework that I provided in Chapter Four (ESP) enhances the practicality and usefulness of SP for front-line caregivers for deception in healthcare. I think each of the authors mentioned in this chapter are devoted to creating practical methods for resolving ethical dilemmas, however this is one important component of resolving a dilemma. The process must also not dilute ethical deliberation, but be robust and provide adequate justification for the chosen alternative. I believe that the process I have outlined in Chapter Four provides both a practical and morally defensible framework for making ethical decisions for cases of deception. In the next brief section I will describe further modifications that I propose for ESP in order to address the issues of both practicality and moral justification.

### **Modifications to ESP**

I argued that SP, in the embedded framework that I discussed in Chapter Four (ESP), is the most ethically practical and defensible framework for deliberating on deception in caregiving. I

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57. Ibid.

will briefly outline several ways in which I have modified SP in the context of deception in caregiving.

First, I utilized two different decision-making levels – organizational and clinical. The organizational level distinguished the constraints on deception and the necessary conditions when it would be morally inappropriate/appropriate to use deception based on the consistent major factors that have significant consequences in cases of deception. These conditions could be used to create a policy for organizations and institutions. The clinical decision-making level provided a step-by-step guide for caregivers to think carefully about each specific critical factor in the unique situation for which a decision should be made. Beauchamp and Childress offer SP and the process of weighing and balancing principles. These components are incredibly important factors in the decision process, but require additional steps as outlined in Chapter Four. Along with the principles they propose I have included trust, deontological, consequentialist and virtue ethics considerations. I believe that attempting to include these categories within the standard four biomedical ethics principles would dilute their important contributions to ethical deliberation. These additional considerations extend to include other stakeholders in the decision, including the caregiver(s) and the impact of the decision on caregiver(s). Although one could attempt reduce these consequences into the other four categories, I think it is important to keep decision-making focused on patient-centered care, while also thinking about the broader context within which a patient is situated. Keeping them distinct helps to isolate and distinguish what is best for the patient and what is possible from a caregiver perspective as well.

I have also included Beauchamp and Childress's guidelines and Bok's publicity test to reduce arbitrariness. These guidelines and the publicity test are another check and balance to help reflect on the moral appropriateness of a decision.

### **Conclusions**

In this chapter, I explored three major methodological objections to SP within the framework that I developed in Chapter Four, ESP. I first reviewed two major bioethics considerations: narrative bioethics and feminist bioethics. I argued that these seeming rival specialties can actually be important components of the ethical framework that I presented in Chapter Four. They can and should be incorporated in ESP.

I then explored three objections to ESP. These objections related to non-arbitrariness, systematicity and casuistry. I argued that despite each of these objections, ESP is consistently practical and ethically defensible. The benefit of ESP is that it is a comprehensive framework, not only as a practical and useful method, but also as a robust and ethically defensible process.

## Conclusion

Deception is prima facie morally indefensible and should be avoided under most circumstances in caregiving. There are, however, limited situations when deception should be considered as a morally defensible alternative in caregiving. These situations require robust consideration and should not be taken lightly. The negative outcomes of allowing deception to be permissible and defensible in caregiving can be very severe and, thus, require significant benefits to outweigh when it should be implemented. Nonetheless, I have argued that there are some very rare circumstances when it is the most morally defensible alternative. I specifically discuss cases where patients lack mental capacity to make certain decisions for themselves. These situations are often when a patient is significantly declining with no chance of recovery and there are no other plausible alternatives with a higher benefit-harm ratio. Other more rare circumstances would occur if there were significant chance of benefit to the patient, little chance of harm or risk and no other plausible alternative. In this type of case, disclosure would be necessary to avoid future harm, if possible. Other specific guidelines for these types of cases and when it would be morally defensible or indefensible were outlined in Chapters One through Four.

To defend this position, my thesis had several key sections. First, I described the problem of deception in caregiving by reviewing the literature to describe how frequent deception occurs in caregiving environments and the major consequences of its use. There were also articles describing its perceived benefits and challenges. Many of those whom had experienced deception and were later notified did not appreciate being deceived, yet were also thankful for being treated when in need of intervention. Additionally, the use of deception in healthcare is poorly tracked and documented, a great concern for discerning whether it is being used in morally defensible or indefensible situations.

In Chapter One, I explored two forms of deception – active and passive. I argued that there are no morally relevant differences between these two forms through an analogous case (active versus passive euthanasia). I compared four points of traditional contention, including intention, consequence, cause and naturalness (expectations), and concluded that these are not morally relevant differences between active and passive forms of deception. Within this discussion I amended the definition of deception to consider the expectations of the person being deceived – that she would have wanted to know the information and/or would have found the information useful for her own ends.

I also reviewed the current philosophical arguments forwarded against and in favour of using deception and described why I believe they are inadequate. The Autonomy and Trust Accounts dominate the current philosophical landscape in describing the conflict, and I argue that the conflict is a multi-faceted issue, including these values along with a pluralism of other values. Traditional arguments regarding deception focus on a dichotomy of the principle of beneficence in conflict with either autonomy or trust. For the Autonomy Account, I argued that even when patients lack capacity to make their own decisions, known autonomous wishes and values are still important for substitute decision-makers and care providers to aid in decision-making. For the Trust Account, I argued that there are many forms of trust that can be utilized, which do not necessarily involve direct truth-telling. These forms can be deceptive, but have a lesser impact on trust relations. I proceeded to describe the ethical dilemma as being much more nuanced and consisting of multiple principles in conflict, including those previously mentioned as well as notions of justice and non-maleficence.

I examined various seeming alternatives to deception and described in detail the concerns with each in the second chapter. I explored the benefits and limitations of each

physical restraints, advance care planning and absolute truth-telling. I further argued why deception could be a plausible alternative in some circumstances, especially when weighing balancing the various ethical principles described in Chapter One.

My third chapter explored several factors in favour of and against the use of deception in caregiving beyond the traditional bioethics principles. First, I explored several legal and professional constraints on deception, including informed consent, the right to choose/right to refuse healthcare in a Canadian context, the right to personal health information and professional honesty. I then proceeded to examine deontological factors either in support of or against the use of deception. I discussed human dignity, the intrinsic value of truth and universality, setting aside the latter two in the clinical decision-making process. The consequentialist considerations for deception included the constraints and limitations of healthcare providers and caregivers more broadly. Lastly, I reviewed two arguments made from a virtue ethics perspective and concluded that virtues are an important component of the decision framework, but need to be supported and given more content through the traditional biomedical ethics principles, as well as other morally relevant considerations.

In Chapter Four, I further created and articulated an original framework through which we can examine cases of deception. First, I focused on organizational constraints and necessary conditions from which healthcare administrators can formulate policies on this issue. The constraints on deception include: mental capacity, compliance with treatment (when applicable) and risk of significant distrust. The necessary conditions include: significant chance of recovery, disclosure and controlled environments. Second, I developed a case-based framework to be utilized by caregivers struggling with the decision to deceive, which included legal and professional constraints, as well as specified principles. I called this new framework

ESP (embedded specified principlism). The aim of the framework is to be both practical and to provide comprehensive moral justification. I further discussed how one could weigh and balance these morally relevant factors.

In my final chapter, I argued that ESP is the most practical and morally justifiable approach to addressing this issue. I explored several other bioethics models, including feminist and narrative bioethics, and argued that these ought to be incorporated into ESP to highlight the importance of reducing stigma towards vulnerable/marginalized populations, fostering greater trust and other relationships between caregivers and patients and understanding the rich narrative of each unique patient. I further explored three major objections to traditional SP including arbitrariness, systematicity and casuistry. I argued that Beauchamp and Childress' guidelines as well as Bok's publicity test are two ways to reduce arbitrariness. I further discussed systematicity and casuistry and how ESP is a practical decision process for ethical decision-making in healthcare, as well as being both comprehensive and robust.

Further research to be explored in the area of deception in caregiving is empirical research on tracking and monitoring the use of deception much more carefully in healthcare and caregiving to determine more precisely further consequences of its use. It would also be extremely useful to examine the impacts of each alternative to deception, as well as deception and its various forms, again to empirically determine the consequences, and patient and caregiver experiences of the use of these various forms.

In conclusion, I argued that deception in caregiving should be extremely limited. In general, its use is morally indefensible, unless a patient's specific circumstances provide strong reasons to act otherwise.

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