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**The Intersections of Hope, Health, and Illness: Moral Responsibilities of
Health Care Providers**

by

Christy Simpson

**Submitted in partial fulfillment of the
requirements
for the degree of Doctor of Philosophy**

at

**Dalhousie University
Halifax, Nova Scotia
November, 2000**

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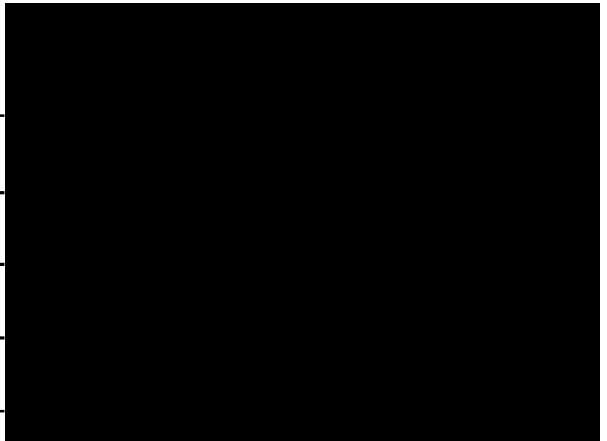
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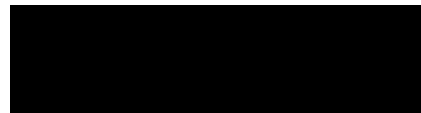
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Abstract

While there is evidence in theory and in practice that hope makes a difference to patients' experiences of illness or injury, the ethical aspects of attending to patients' hope(s) have been largely ignored in philosophy and bioethics. In this project, I investigate the role of hope in health care and argue that health care providers have a responsibility to foster conditions within which patients can discover and continue to have hope. Stories from patients in four clinical contexts (terminal illness, mental illness, chronic illness, and rehabilitation) assist in identifying important, and often overlooked, features of hope such as the role of imagination and the vulnerabilities of patients connected with having hope. The new definition of hope I develop demonstrates that hope is salience-determining and action-directing. Hope also has strong relational features; the relationships patients have and the context within which these relationships are formed and played out can substantially influence what they hope for as well as whether they are able to hope. On this basis, I argue that the responsibility of health care providers is best situated within a feminist care ethics approach. This approach lends itself well to demonstrating what can go wrong with certain practices of care and assumptions about what are "reasonable" hopes for patients to have and generally provides a framework for understanding the role of hope in health care. Finally, I explore the normative implications of the responsibility to foster conditions within which patients can discover and continue to hope demonstrating that there are actions health care providers can take within current structures to address patients' hopes. Moreover, the structural barriers to performing well the required caring hope work can form part of a larger critique of the health care system.

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Chapter One

Introduction

Hope is not tidy! It cannot be confined in nice neat chapters. Rather it weaves itself like an essential thread through thoughts and experiences that speak of the human condition. It is not the only thread of existence, simply a vital one. If it breaks or frays, our lives are still intact; but if it is removed, our lives start to unravel.
*Ronna Jevne, "This Thing Called Hope," *The Quest**

1.1: Why Hope?

It is widely recognized in theory and in practice that hope can make a difference in patients' experiences with illness or injury and in how they live their lives. Frequently, attending to patient hopes has been cast in terms of physicians and other health care providers having an "obligation to promote reasonable hope for patients..." (DeVita, Hellman, and Rosenburg 1997, 2974). This implies that the obligation to maintain and promote patient hope is of comparable importance to other well-recognized obligations of physicians, such as informed consent. But it is not clear what this duty is nor whether it results in morally appropriate actions by health care providers. For these reasons, the role of hope in health care merits ethical analysis.

Remarkably little attention has been paid to hope by bioethicists and by philosophers in general. In philosophy, when it is discussed, hope is often explored in the philosophy of emotion, i.e., what sort of an emotion is hope? While these analyses of hope provide some insight into the necessary and sufficient conditions of hope, there generally is no further exploration of the meaning of hope to individuals and what role hope may play in their lives. In bioethics, when hope is mentioned, it is typically treated as one of the

minor issues to reflect upon in discussions of telling the truth to patients or breaking bad news. One recent publication in bioethics aims to draw our attention to the moral importance of hope; this is an article by William Ruddick (1999), "Hope and Deception." Ruddick highlights a number of issues with respect to hope and clearly demonstrates the complex nature of hope and its role in health care; he shows that sweeping generalizations about the benefits and harms of promoting hope(s) for patients cannot be sustained. Ruddick ends his article with a call for further investigation of this neglected topic. Although my interest in and work on hope had started before Ruddick's article appeared, I see this project as part of the necessary work he identified.

A series of related questions informs the focus of this work. These questions include: What is hope? What is the value of hope in the clinical setting? How can health care practitioners enhance a patient's experience of hope without denying the reality of disease? Do health care providers have an obligation to promote hope for (all) patients? How might uncertainty with respect to the illness experience influence hope or the ability to maintain hope from both the patient's and the practitioner's perspective? Does the role hope plays in health care change depending on the clinical context and, if so, what are the ethical implications of these changes? Do health care providers have an obligation to try to cultivate their own sense of hope? Answers to these questions will be worked out with the assistance of patients who have described their experiences with hope in the context of illness and injury.

1.2: Patients' Experiences with Illness and Injury

A fundamental principle of this thesis is that patients' experiences of hope must be central to my analysis. If I am going to investigate the ethical aspects of the role of hope in patients' lives as they cope with illness or injury and how health care providers can best attend to patient hopes, then this investigation should be informed by patients' experiences. Clearly I cannot possibly canvass all clinical contexts for patient stories nor expect to represent all injuries or illnesses. As such, I have decided to limit this analysis of hope to (adult) patients in four different areas of health care, namely terminal illness, chronic illness, mental illness, and rehabilitation. Hope is most often discussed in terms of terminal illness: is it possible for patients who are dying to hope? What should they hope for? For a balanced investigation of hope, it is important to consider what hopes patients might have in a variety of clinical contexts since patient hopes may change or be different from hope in terminal situations. When we consider, for example, persons with chronic illness in contrast with persons with mental illnesses and with persons in rehabilitation, it seems likely that hope will play a significant role in all these patients' lives and will raise different questions/problems with respect to how health care providers should attend to the hope(s) of these patients. The "hope stories" I use in this work will provide insight into the nature of hope as well as what can and ought to be expected of health care providers with respect to hope in these clinical settings.

While I will use a variety of stories and examples in this project, let us now meet two patients whose stories will frequently inform and direct this investigation. Morrie Schwartz is a former college professor in his seventies who is diagnosed with amyotrophic

lateral sclerosis (Lou Gehrig's disease or ALS). ALS is a progressive, fatal neurological disease where the person gradually loses control over their motor functions due to a loss of muscle neurons. People with ALS typically live less than five years from the time they are diagnosed with this disease. Mitch Albom, a former student of Morrie's, reconnects with Morrie in his last few months of life. The book, *Tuesdays with Morrie*, from which I draw quotes by Morrie is written by Mitch and details their Tuesday conversations with each other and the lessons he (Mitch) learns about such topics as life, death, family, and forgiveness. These are lessons about how to live one's life well that Morrie hopes Mitch will share with others. The honesty with which Morrie shares how ALS has changed his life and continues to change his life as it progresses, and how he deals with these changes, provides a rare insight into what it is like to face death and disability - with fear, anger, sadness, and hope. As Morrie says, "Once you learn how to die, you learn how to live." (Albom 1997, 82)

Bonnie Sherr Klein is a successful documentary film maker with the National Film Board who, in mid-life, suffers a relatively mild stroke, begins to recover from it, and then suffers a second devastating stroke a month later. As soon as Bonnie could work a pencil, she kept a journal that forms the basis for her book *Slow Dance: A Story of Stroke, Love, and Disability*. Along with interviews with her family and friends and excerpts from her medical chart, Bonnie introduces us to the world of recovery, rehabilitation, and life with disability. Bonnie's journals and her book are her way of "[w]riting myself into understanding, into recovery of myself." (Klein 1997, xii) A variety of health care providers from nurses to physicians to speech therapists and physiotherapists play a role

(both positive and negative) in Bonnie's lengthy, difficult, and sometimes frightening process of recovery of her body's functions and, most importantly, herself. Consider what Bonnie has to say about five months after her second stroke:

I had a bad experience in *ergo* [physiotherapy] this morning. An old patient of Evelyne's [physiotherapist] came by to say hello - he walks with one cane and is still unable to work after two years. I wonder what he does all day. Evelyne offered him as a hopeful model, saying he was like us when he began. All I could see was the cane and the limp, and I got suddenly depressed and tearful. When Evelyne asked why, I said I'd expected to go much further, in fact to play tennis this summer. Evelyne broke into uncontrollable laughter at the idea, it seemed so preposterous. I was devastated. She apologized later, though she said she'd be enormously surprised if I could ever run again. She allowed as how it might be helpful to hold onto an image, however unrealistic. She said she hoped she hadn't been too brutal in making me confront reality.

I spent the rest of the day in my room, without the energy to continue. Part of me refuses to believe her, refuses to give up. The other part says there will be no more heroics, no dramatic recovery, just days and weeks and months of hard work with no defined end-point, no light at the end of the tunnel. What's the point? After the ecstasy of survival, what exactly have I survived for? (Klein 1997, 247-248)

Both Bonnie's and Morrie's stories force us to ask questions about what makes a difference in how patients deal with sudden or gradual changes in health and the implications of these changes in how they live their lives and understand who they are. I will supplement these two stories with, among others, those of: Darcy - an artist with lymphoma (cancer); Stephen - a minister with Chron's disease (a chronic, progressive, inflammatory disease of the bowel); Kay - a physician with manic-depression; and Charles - a physician with a spinal cord injury. Through these stories, the importance of attending

to the context within which patients hopes are discovered and destroyed as well as who is involved is demonstrated. The role of health care providers in enhancing/inhibiting the ability of patients to hope is clearly articulated by these stories and, in effect, they call out for an analysis of the moral responsibilities of health care providers with respect to what patients hope for.

1.3: Outline

In order to discover what the moral responsibilities of health care providers are with respect to patient hope, I need to be able to say what hope is, ground my analysis in a moral framework, and test out possible formulations of what could be expected of health care providers. As I stated at the outset of this Introduction, health care providers are often told that they have a duty to promote hope in patients. In Chapter Two, I question both the justification of this duty as well as its formulation. Although there is evidence that hope has psychological and physiological benefits for patients, indicating that it “would” be better for patients to have hope than not, this evidence does not seem to supply adequate justification for the health care providers’ duty to promote hope (as it is commonly expressed). In particular, I am concerned that this approach to patient hopes: (1) requires health care providers to promote hope without giving sufficient attention to what hopes should be promoted; and, (2) places patients in a passive role where the health care providers are the ones doing the work to “make” the patient hope and this may thereby exacerbate the power imbalances that exist between the patient and health care providers. Ultimately, I argue that this duty should be reformulated and propose the

following instead: Health care providers have a responsibility to foster conditions within which patients can discover and continue to have hope. I explain and defend this reformulation, paying close attention to the shift from a *duty* to a *responsibility*.

Completing this chapter, I consider and reject an alternate formulation, a principle of respect for hope.

Before I can proceed to discuss what fostering conditions for patient hope may ask of health care providers, I need first to define hope and describe the normative framework which will guide and inform the application of this responsibility. Chapter Three takes on the task of defining and conceptualizing hope. Given that “hope” is a word that is commonly used in our language, it is important to state what my definition of hope will and will not do. First, my definition is developed within and for the context of health care, based on patients’ experiences with illness and injury. As such, I do not claim that my definition of hope will apply to uses of this word beyond the boundaries of health care. Second, even within health care, my task is not to describe the necessary and sufficient conditions for all uses of hope, but to identify: a) the aspects of hope that are common to most understandings of hope in health care and b) the aspects of hope that are unique or of particular importance for patients and their experiences of illness or injury and thereby need to be emphasized in the new definition. By exploring selected historical accounts of hope, namely those by Aquinas, Hobbes, Hume, and Descartes, as well as a phenomenological account of hope by James Muyskens, I am able to develop a sense of what features of hope are common to most definitions and will still apply in the context of health care. One aspect of hope - the role of the imagination - is rarely discussed and I

demonstrate that an important part of patients' being able to cope with their illness or injury is the ability or opportunity to imagine themselves, for example, getting better, remaining stable, or managing to deal with the changes that their illness or injury has created in their lives. Third, I expect that my definition should fit with and help to illuminate ethical debates about the role of hope in health care, such as what is at stake with "false" hope. The definition of hope I arrive at contends that hope is an emotional attitude (with four conditions) and that it is thereby salience-determining and action-directing. Finally, I end the chapter with a comparison of hope to optimism and wishing and to hopelessness, despair, and fear.

Chapter Four begins with a discussion of vulnerability as it pertains to patients and their hopes. I identify three ways in which patients are vulnerable with respect to their hope and argue that the relational aspects of hope must not be ignored. The relationships and interactions that patients have with others, including health care providers, can significantly affect both the ability of patients to hope and what they hope for. As such, it becomes important to employ a normative framework that can not only accommodate this aspect of hope, but can highlight it and provide the necessary critical and evaluative "tools" for determining what the responsibility to foster conditions for hope means, given the relational aspects of hope.

...[care ethics] can serve as corrective to the all too common tendency among health care providers to regard patients only in their generality—as repeatable subjects of generic care—ignoring particularities essential to understanding the situations of sick and vulnerable individuals. (Donchin and Purdy 1999, 9)

Accordingly, I argue that a feminist care ethics approach is best suited to this task and, in particular, draw upon the work of Joan Tronto.

I next turn to some “deeper issues” with respect to practices of care as they relate to what are considered to be “reasonable,” “legitimate,” and “realistic” hopes for patients to hold. The aim of Chapter Five is to demonstrate that it is not always clear what are reasonable hopes for patients to have and that certain practices of care will need to be revised. I first review the results of a study by Anssi Perakyla that describes common conversational patterns between seriously ill patients and health care providers. These conversational patterns tend to narrow the choices of what can be hoped for by patients to either the hope for cure or the hope for palliation. My critique of these conversational patterns paves the way for an in-depth discussion of “false” hope. I argue for a change in terminology; namely, that we should think about categories of uncontested and contested hopes (of which false hopes form a small sub-category). Next I explore the reasons typically given for contesting patients’ hopes and reveal the context-dependent and person-relative nature of these challenges. Although I do allow that some patient hopes can be legitimately contested, the decision to intervene must be approached with sensitivity and caution. Finally, the dynamic and interactive nature of what patients hope for is further demonstrated as I discuss how patients’ self-understanding and self-definition may change, and continue to change, as they learn about who they are in the context of illness or injury.

Chapter Six discusses the normative implications of the health care providers’ responsibility to foster conditions within which patients can discover and continue to have

hope. I explore the nature of this responsibility and argue that health care providers can be best understood as “supporters” or “backers” of patient hope. On this basis, I proceed to ask: what should health care providers do? What are the changes that need to be made to their practices of care? I begin answering these questions by surveying the strategies suggested in the hope literature for enhancing patient hopes and contend that critical gaps exist in these strategies. The most important gap is the failure to acknowledge the fact that health care providers can affect what is hoped for in all of their interactions with patients and, therefore, I argue that health care providers need to address patient hopes in their everyday practices of care. Further, health care providers’ own hopes need to be considered as what they hope for can influence and affect how they understand and fulfill their responsibility to foster conditions for hope. Some of the more practical features of the organization and structure of health care, for example, time and privacy, are also addressed as they impact on the conditions for hope. I finally explore both how “more distant” others, such as the government, hospital boards, etc., and the social context of medicine (i.e., prevailing attitudes about health and illness such as the pursuit of cure) play a role in what health care providers can do to foster conditions for hope.

The final chapter of this project takes us back to patients’ stories. It seems only fitting that the first story tell us about care that leads to the ability to find hope(s) while the second story relates how hopes can change with experience. Future directions for this project are also identified.

Chapter Two

Setting the Stage - The Role of Hope in Health Care

Hope is the physician of every misery
Irish Proverb

2.1: Introduction

It is commonly assumed that health care providers, primarily physicians, have an obligation to promote hope for patients - an assumption that carries with it many important questions - yet little in philosophical and, more narrowly, bioethics literature attends to hope and its role in our, sometimes healthy and sometimes ill, lives. In this chapter, I undertake an analysis of the health care provider's obligation to promote hope, questioning both the justification of this obligation and its formulation. To my knowledge, no such previous analysis exists and my goals are to demonstrate why this analysis is necessary and to identify ways in which it can proceed; ultimately, I will propose a new formulation of the "call" for health care providers to attend to patients' hopes. This new formulation will provide the framework for examining the moral aspects of hope's role in health care in the following chapters.

2.2: The role of hope in health care

The claim that hope has a role in health care and that health care providers should attend to patient hope is appealing and seems intuitively right. Most people value their health as a good in itself and also as a means for achieving or enjoying other goods. As such, when an individual's health changes or is threatened, this can have an immediate and

serious effect on her outlook for the future and on what is hoped for. As such, health care's ability to make this individual better or to assist her in maintaining a stable level of health over a longer period of time becomes important. This individual's hopes for the (near and distant) future can become closely entwined with and shaped by the experiences she has in health care and with the health care providers she meets.

During my clinical practicum (Fall 1998) in the oncology departments of two Halifax hospitals, it became apparent that hope was part of the "everyday" practice of health care and was reflected in interactions between health care providers and patients. From the "You'll be feeling better in no time" to the "We'll have to run some more tests, but in the majority of cases this turns out to be benign," many comments, responses to questions, and actions reflected the importance health care providers placed on ensuring patients were "keeping their hopes up." When I mentioned that I was interested in hope to any of the health care providers, the response was very favourable: "Oh yes, I deal with patient hopes all of the time and have a number of questions about it. How much hope should I promote? What hopes should be promoted? Don't I have a responsibility to dissuade patients from false hopes?" These responses indicate to me that health care providers acknowledge both that hope has a role in health care and that they believe they have some responsibility with respect to what patients hope for. Yet, as the responses also indicate, health care providers need, and would appreciate, some assistance with ascertaining just what this responsibility is and how it applies in different circumstances.

2.2.1: Possible responses

Before one even turns to the hope literature to investigate how health care providers are asked to attend to patient hope and the reasons why, one can consider a range of possible responses to the claim that hope has a role in health care. One could argue that health care providers should actively promote patient hope, work to sustain patient hope (where it exists), be neutral towards patient hope (neither encourage nor discourage it), or ensure that patient hope is not destroyed. The grounds for choosing one or some combination of these options should identify the moral status of hope as well as give sufficient justification for the expectation made of health care providers with respect to patient hope. In other words, each of these options makes different normative claims about hope and about what is right and wrong for health care providers to do or not to do with respect to patient hope. For example, telling health care providers to maintain a neutral stance would imply that hope is not within the scope of activities properly undertaken by health care providers and that what is hoped for and/or whether a patient has hope is up to that patient.

Yet, given both the above comments and results from studies on health care providers and hope (see, for example, Perakyla 1991; Miyaji 1993), it is apparent that health care providers do already take a certain position with respect to patient hope - namely, they take an active role in shaping what a patient hopes for and in promoting hope in patients. This general sense that an active role is appropriate is further reflected in the hope literature which states that health care providers have a duty to promote, maintain, and instill hope in patients. Although I will later challenge and reformulate this duty, it is

worth spending some time investigating what is said about it. Examining the role that this duty creates for health care providers and the justification offered for it will provide insight into what, I will argue, is wrong with how hope is currently approached and conceived of in health care.

2.3: Examples of the duty to promote hope

Perhaps it is best to start with a few exemplars of the said duty to situate us in the hope literature. Most references to the obligation to promote hope apply to physicians. In the well-known medical textbook, *Cancer: Principles and Practice of Oncology*, it is claimed in the section on ethics that: “In addition to the obligation to be honest with patients, [physicians have] an obligation to promote reasonable hope for patients with cancer.” (DeVita 1997, 2974) Further, in a study on American oncology and the discourse of hope, physicians reported “a perceived mandate to instill and maintain hope [in their patients].” (Good 1990, 68) While it is easiest to find explicit references to the physician’s duty to promote hope in oncology literature, this obligation is widely believed to extend beyond patients with cancer. For example, the physician’s role in promoting hope is also discussed in relation to persons with HIV/AIDS, persons with mental and chronic illnesses, and persons in rehabilitation.¹

Equivalent claims about hope can also be found in the nursing literature. As Rose McGee sums up in her article on hope:

¹ For example, in his book, *The Illness Narratives*, Arthur Kleinman states that: “Instilling or rekindling hope in the chronically ill patient...is an essential, though poorly charted, clinical domain.” (Kleinman 1988, 244)

Nursing literature reflects the concern of the profession with the concept of hope...From the perspective of nursing as an applied science, the literature outlines role obligations of the nurse in terms of instilling, maintaining, and restoring hope [Adams and Proulx 1975; Limandri and Boyle 1978; and, Vaillot 1970]. (McGee 1984, 35)

In another article, the same assessment of the nurse's role with respect to hope is made:

Nursing literature contains multiple references to hope and the hoping process, directives about the importance of having hope, and of maintaining, sustaining, and restoring hope to patients. (Dufault and Martocchio 1985, 379)

It is interesting to note that similar language is used to describe the duty of both the physician and the nurse to promote and instill hope in patients. Thus, it becomes important to understand why hope is considered to be of such significance in health care to make promoting hope a physician's or nurse's duty.

Moreover, attention to hope in the health care setting is not "only" the doctor's or the nurse's responsibility. While the physician may be the team leader and the one with the most power in the relationship with the patient, and while nurses often have more day-to-day contact with patients, this does not mean that physicians and nurses are the only ones who need to attend to patient hope. For example, the person who takes X-rays can potentially affect patient hope by treating patients coldly, not explaining the procedures, making insensitive comments, and leaving them unnecessarily "exposed" on the table. Patient anecdotes tell of radiologists exclaiming, "Oh my, look at the size of that lump" (or even just an "Oh no" leaving the patient wondering if it is a reference to her X-rays, something that was dropped on the floor, etc.) without the radiologist being aware of the impact this exclamation has on the patient. Further, when the radiologist declines to

answer the patient's questions, telling the patient to wait for the call from her oncologist, this patient waits in fear and dread, not knowing for sure whether she has cancer.

Imagining the worst in these situations makes it difficult to maintain hope.

Further, it is clear in Bonnie's case that other health care providers, i.e., physiotherapists, occupational therapists, speech therapists, all play a large role in her rehabilitation and, consequently, in her ability to maintain or have hope. In some clinical contexts, such as rehabilitation and chronic illness, the patient will see number of different health care providers; physician(s) and nurse(s) do not always have primary and/or prolonged contact with the patient. Thus, these other health care providers need to be included in discussions about hope as well since they also have a role to play with respect to patient hope(s). Accordingly, in this study, I will talk generally about health care providers and hope assuming that, if there is a duty to promote hope, it extends to all health care providers (to the extent that they can influence patient hope). Where necessary, I will talk specifically about certain health care providers, but the majority of the claims I will make with respect to hope will apply to all health care providers.

2.3.1: Justification for this duty

Interestingly, while the claim that health care providers have an obligation to promote or maintain patient hope is made with limited consideration of the ethical implications of attending to hope in health care, even less time in the hope literature is given to the *justification* of this claim (although a few such accounts can be found). The lack of analysis of this justification indicates a serious gap in current discussions that take

this obligation as a given. For example, calling it an obligation puts attending to hope on the same level as other well-recognized (physician) obligations such as ensuring informed consent; however, attending to hope has received comparatively little discussion. Two questions that never seem to get asked about this duty to promote hope are: Is making it a duty the proper or most appropriate categorization for “enforcing” attention to hope for both health care providers and patients? And, if such a duty does exist, has this obligation been formulated correctly? A related consideration is whether health care providers can actually fulfill this obligation. I will argue shortly that the justification of this duty is incomplete and that this duty needs to be reformulated. Chapters Four to Six will discuss and assess the possibility(ies) of health care providers being able to fulfill the requirements of this reformulation.

As I take it, the request for justification of the duty to promote hope can be addressed to two aspects of this duty: first, one can request justification for the emphasis on hope, i.e., why focus on hope in patient care (as opposed to happiness or well-being)?; and, second, one can request justification for the manner in which health care providers are “asked” to attend to hope, i.e., why is it an obligation to promote, maintain, and instill patient hope (as opposed to, for example, a responsibility to not destroy hope)? Although the answers to these two separate requests for justification will obviously be interrelated, I will demonstrate that even if we establish that hope is valuable, this does not imply that there is a duty to promote it. In particular, it will become apparent that many of the reasons given for attending to hope in health care are framed within a medical perspective in terms of medical goals. While these goals and reasons are important, this is only one-

half of the picture - the patient's perspective is missing. Why hope is important to patients and how patients understand the role of hope in health care is typically not addressed in these articles and, without this perspective, an erroneous approach for attending to patient hope is endorsed, namely the duty to promote hope.² In the following three sections, I will present and critically examine: first, the medical perspective on why hope is important; second, the justification for the duty to promote hope for patients; and third, the patient perspective on hope. Ultimately, a number of reasons for revising the duty to promote hope will be identified.

2.4: Why hope? The medical perspective

Why hope? One of the first responses to this question is that hope is a crucial part of human life; that without hope, people feel lost, that life isn't worth living. Eric Kodish and Stephen G. Post, among others, describe hope as a central element of human experience, an element that is expressed in a variety of ways in all human civilizations (see Kodish and Post 1995, 1818). Accordingly, they continue, hope has naturally long been part of the healing professions; it has been of value in health care and has been fostered in patients. Yet despite this said importance of hope in healing, Kodish and Post (1995) note that attitudes with respect to hope's role have changed over time: "In reaction to a history of deception in order to preserve hope, many now think that hope has no role in our

² I will argue below that this duty is not sufficiently responsive to the context within which patient hopes are "promoted," especially in terms of who the patient is.

thinking about clinical medical ethics.”³ (1818) They argue that this situation should change and suggest that, “...hope should not be entirely dismissed, for it is one major mode by which people anticipate the future.” (Kodish and Post 1995, 1818) This latter point is instructive as it offers a more specific explanation for hope’s importance in health care: hope concerns our future - what we think it will be and what we want it to be. Given the uncertainty that often accompanies many illness experiences - will I be sick for a long time? will I get rid of this cancer? will I be permanently unable to walk? - hope helps patients, and health care providers, to reconcile this uncertainty with their desires for the future. And the underlying claim is that anticipating the future with hope is “better” than anticipating it with fear or despair (other major modes of anticipating the future).

This claim is supported, in turn, by empirical evidence. Studies suggest that hope promotes healing (Gottschalk 1985; Udelman and Udelman 1985a, 1991; Cousins 1989), facilitates the coping process (Herth 1989; Elliott et al. 1991), and enhances quality of life (Staats 1991).⁴ In other words, hope helps patients to emotionally endure crisis (Miller 1989), especially major disabilities or life-threatening illnesses (Mader 1988). As well, there is evidence to suggest that patients with hope follow treatment recommendations more completely and tolerate discomfort better than patients without hope (Bruhn 1984; Buehler, 1975; as described in Wong-Wylie and Jevne 1997). There are also studies that

³ This quote also comments on how hope is sometimes perceived, i.e., as potentially being in conflict with other health care obligations, and demonstrates that it has wrongly been used to justify deceiving patients; I will outline some of these concerns in Chapter Seven.

⁴ These studies are summarized in Nekolaichuk, Jevne, and Maguire 1999.

demonstrate: a) a connection between the loss of hope and suicide (Beck, Steer, Kovacs, and Garrison 1985); and, b) that the loss of hope and the generalization of hopelessness is associated with personal depression (Brown and Harris 1978).⁵ Thus, it can be said that hope, or having hope, is “positively linked to health” (Nekolaichuk, Jevne, and Maguire 1999); hope has therapeutic value. One possible exception to this general rule could be false hope: if patients have false hope, it is often felt by health care providers that the benefits of hoping are much less obvious and the potential harms great (more will be said about this in Chapter Five).

Thus, as found in the literature, the answer to the first request for justification is that attention to hope in the clinical setting is warranted by three primary yet interconnected factors: a) hope is an important aspect of human life; b) hope likely has positive physical effects;⁶ and, c) hope also has positive psychological effects, since it helps individuals to deal with uncertainty when their health is threatened. Once one or all of these reasons have been identified in an article or study on hope - and frequently only the latter two factors are mentioned - the authors quickly move to recommending appropriate interventions and strategies for promoting hope in patients. For the most part, these reasons are taken to provide adequate evidence that hope needs to be promoted in

⁵ These studies and others are reported by Kenneth P. Nunn (1996) in his article, “Personal hopefulness: A conceptual review of the relevance of the perceived future to psychiatry,” *British Journal of Medical Psychology*, 69: 227-245.

⁶ Investigations into this connection between the mind and body in relation to hope’s effects is sometimes discussed in terms of hope’s psychopharmacological properties. For example, it may be that having hope increases the effectiveness of one’s immune system.

health care. I do not dispute that these are good reasons for attending to patient hope. However, these reasons predominantly focus on the medical benefits of hope, i.e., hope should be fostered in order to help further the goals of health care, namely to improve the physical and psychological health of patients. But what about the answer to “why hope” from the patient’s perspective? The answer given from this perspective provides different, and important, reasons for attending to hope in health care, reasons that encourage a broader reflection upon hope’s role in health care (see Section 2.4.2). Before turning to the patient perspective though, it is worth rounding out the discussion of hope from the medical perspective with a look at the justification given for the duty to promote hope.

2.4.1: What is the justification?

In this section, we move from answering “Why hope?” to asking what the justification is for the health care provider’s *duty to promote, maintain, or instill hope*. Again, when it is mentioned in the literature, most of the discussion of the justification of this duty has focused primarily on how this duty applies to physicians and, to a lesser extent, to nurses. Given this, let us look at what justification is given for physicians having a duty to promote hope.

“By their words and actions, physicians can be powerful modulators of patients’ hope.” (Kodish and Post 1995, 1818) Kodish and Post emphasize that physicians, by virtue of their interactions with patients and, I would add, their position in health care and in society, play a critical role in whether a patient is able to hope and what that patient hopes for. As Howard Brody (1981) puts it: “The physician is placed in a pivotal role to

influence the patient's ideas and emotions for better or for worse." (1411) Thus, it seems that one reason for wanting, at least, physicians to intentionally address patient hope is simply due to the fact that physicians can affect patient hope.⁷ Indeed, there are studies demonstrating that such actions by physicians as listening to their patients, reassuring their patients that they will not be abandoned, and taking the time to answer patient questions can positively influence the hope of patients (see Nikolaichuk, Jevne, and Maguire 1999; Wong-Wylie and Jevne 1997). While this evidence suggests that there are actions physicians can employ that positively affect patient hope, does this evidence provide the necessary justification for making it a duty to promote hope?⁸ The listed examples of actions are not, I would argue, unique to fostering hope; in fact, they seem to be more generally part of what is already expected in medical care (however well these are carried out in actual practice) and thereby do not seem to motivate this separate claim for the physician's duty to promote hope.⁹

Once again, I turn to Kodish and Post who provide a summary of the justification (as they understand it) for the duty to promote hope.

This obligation is based on respect for the remarkable healing powers of the human spirit, responsibility for promoting the psychologic and physical health of patients,

⁷ Note that this focuses on the power of the physician with no further attention given to the nature of this power and why they have it from the patient's perspective.

⁸ If the concern is that health care providers not negatively influence patients' ability to hope or leave them without any hope (in despair, for example), the duty could be worded instead as a duty to not destroy hope or to not leave patients without hope.

⁹ A parallel analysis can be made of the nursing literature and the duty to promote hope (see McGee 1984, Dufault and Martocchio, 1985).

and humility in understanding the limitations of a clinician's ability to predict the future with certainty. (Kodish and Post 1995, 1821)

A similar description of the justification for this duty to promote hope is offered by Kodish, Peter Singer, and Mark Siegler in the oncology textbook by DeVita et al:

This obligation to encourage hope derives from several sources: the still poorly understood relationship between the mind and the body; the physician's responsibility for attending to both the psychologic and physical needs of patients; and humility in understanding the limitations of a clinician's ability to predict the future for any given patient. (DeVita 1997, 2974)

With respect to this first reason, the only real difference between these two descriptions is the relative weight attributed to the healing power of the human spirit/the mind and body connection. This reason attempts to capture the "as yet" unexplained (from a scientific perspective) aspects of hope's influence on the health of patients. The second reason in each description is very similar to the reasons offered in Section 2.4 for focusing on hope in the clinical setting, namely that fostering hope assists in improving the physical and psychological health of patients. The third reason provided turns on uncertainty emphasizing the fact that, although there may be statistics and prognostic information for a given disease or injury, the physician does not know for sure how an individual patient will do - as such, offering hope to patients may be an appropriate response for dealing with this uncertainty. In other words, in the absence of certain knowledge about what may happen in the future, hope may be an appropriate response by patients and is a response that should be encouraged by health care providers.

Ultimately, as it is portrayed in the literature, the reasons offered for the health

care provider's duty to promote hope rest primarily on the previously identified positive benefits of hope as well as on the health care provider's role in the healing process and life of the patient. Indeed, it is true that health care providers may have a powerful influence on patient emotions, including hope, and ought to use this power wisely or appropriately, i.e., for the benefit of the patient; at least, they should acknowledge where the limits of their power lie, such as in not being able to predict the future with absolute certainty. However, I am still left somewhat unsatisfied by the explanation: has the positive duty of health care providers to promote hope been justified on these grounds?

It still seems that little explanation for the formulation of the obligation to promote hope has been given; two questions of particular importance have not been answered. First, does being in a position of power and influence over someone else's emotions automatically entail an obligation to promote, instill, or maintain certain emotions in that individual, especially given evidence that those emotions are likely beneficial? Health care providers do need to respond to the fact that what they say and do will affect patients' emotions, but it is not clear that the positive duty to promote hope is the best way to describe or capture what this response should be. In other words, more needs to be said about what the responsibilities of health care providers should be with respect to their patients' emotions and the actions that stem from these emotions. Second, why is the obligation worded as it is, as a positive duty, instead of as a duty to not destroy patient hope?¹⁰ Many feminists, for example, have demonstrated that relative differences in power

¹⁰ An obvious argument against this duty to not destroy hope is that this may seem to place health care providers in a position where they ought to withhold information from patients or not tell patients bad news. What I am trying to do here is not necessarily

exist between patients and, primarily, physicians (on the basis of education, income level, gender, and race etc.) and that this imbalance can have a negative impact on such things as patient participation in care (see, for example, Sherwin 1992). As such, it seems important to ask whether a duty to promote hope will exacerbate this power imbalance by giving more control over patients' emotions to health care providers than is necessary. These questions pinpoint the difficulty I have in accepting both the duty, as it is worded, and the justification offered thus far. As will become clear in Section 2.5 below, I believe a different approach to hope in health care is more plausible and more ethically defensible - and it is also one that can respond to these concerns.

2.4.2: The patient perspective - health care as a symbol of hope

It is interesting that the justification cited for placing an emphasis on patient hope is often only stated in medical terms and with respect to medical outcome measures (for example, improved physical health), especially when it is patients whose hope is at issue. Patient expectations of health care are a critical, fundamental part of addressing "why hope?" and "what should the role of health care providers be?" with respect to patient hope. Given that what patients expect and value will and should have a primary role in what is hoped for, it is a major oversight to talk about hope and discuss its positive effects separate from the ideas and expectations that patients have of their health care providers and of health care in general.

endorse this negative duty, but to suggest that other formulations of this duty should, at least, be considered to determine whether the duty to promote hope is the best version.

In many ways, health care has become a symbol of hope. With all of the advances in medical knowledge, technologies, and pharmacologies as well as in genetic research, many people believe that “the cure is just around the corner” and may even be available at the nearest hospital. If you are feeling bad, the doctor, the nurse, the physiotherapist, can tell you what is wrong and will be able to make it better is an assumption most of us make.

Modern Western medicine plays into and conforms to our cultural myth that the body can be controlled. Collectively, doctors and medical researchers exhibit very little modesty about their knowledge. They focus their (and our) attention on duress and imminent cures, on successful interventions...Doctors are trained to do something to control the body, to “make it better” (Kleinman, 1988); they are the heroes of medicine. They may like being in the role of the hero, but we also like them in that role and try to keep them there, because we want to believe that someone can always “make it better.” (Wendell 1993, 234-235)

Research on the “placebo effect” also indicates the power of believing that something is being done to help you. The placebo effect is described as, “...a change in the patient’s conditions that results from the symbolic dimensions of a healing intervention rather than from its specific pharmacological or physiological properties.” (Brody 1992 , 132) In other words, if an individual believes that she will be helped or is being helped, a positive effect on her health or outlook can often be measured. As Howard Brody (1981) says, “We know from placebo research how potent the patient’s emotions and ideas can be in healing the body.” (1411)

While the hope that health care can offer assistance or, even, can “fix everything” can add to the placebo effect, one cannot assume that this is the best hope for patients to hold nor the most important hope for each patient. One of the dangers of this hope in

health care being set too high in terms of technological and pharmacological cures is that patient hopes can be dashed, not only by finding out, for example, that their “little” problem is actually a chronic illness, but also by finding out that there is no cure or no easy procedure. Health care providers need to be aware of how strong these cultural hopes can be for some patients and to be able to respond to these hopes. Another consideration is that this expectation that we will be cured by the health care system, while prominent, should not be taken to be all-encompassing for every patient. For some patients, the hope will not be for cure, but for a label that tells them that what they are experiencing is real, or for someone to listen to them, or for acknowledgement that one is doing all one can in rehabilitation or coping with chronic pain, or for a supportive gesture and a kind word. In effect, health care represents a place where we will get *care* or be *cared for*; all patients hope for this in one respect or another. Thus, knowing that patients regard health care and individual health care providers as a symbol of hope establishes another, critical, reason for arguing that health care providers have a responsibility to attend to patient hope. This reason demonstrates that hope is not something “extra” that may or may not be part of patient care, but that hope is, to greater or lesser degrees in different clinical contexts, an ever-present element of health care. My concern then is that the duty to promote hope may not be sufficiently responsive to these contextual aspects of patients’ hopes.

2.4.3: The critique of the duty to promote hope

In light of the power health care providers (not just physicians) do have over patients and how much they can influence patients’ emotions, as exemplified in Bonnie’s

case when the physiotherapist laughed at her hope to walk again, I am concerned with how the duty to promote hope is formulated and likely to be interpreted: that health care providers promote, maintain, or instill hope in patients tends to emphasize the outcome, i.e., that the patient hope, rather than the process, i.e., how the patient arrived at that hope, and what that hope is actually for, namely, whether the hope truly reflects the patient's own desires and values. From an ethical perspective, it seems that the process by which hopes are generated is just as, or perhaps even more important than, the outcome. This claim relies on the belief that, in order to respect patients as persons, it is not right for health care providers to promote hope just for the sake of the potential medical benefits of this emotion. In other words, what the patient hopes for, not just whether the patient has hope, is morally important. If the health care provider, for example, lies or withholds information from the patient in order to instill hope, this can have serious effects on the patient-health care provider relationship if/when the deception comes to light (and is morally suspect even if the deception is not revealed). To put it another way, the benefits of patients having hope do not seem to justify (in most cases) overriding other ethical norms, such as patient autonomy.¹¹

Another concern with the given formulation is that the obligation to promote hope can be interpreted or read as implicitly reinforcing a certain relationship between the health care provider and the patient, i.e., one in which the patient is passive and the health care

¹¹ More will be said about this in the following chapters, but I do not want to be understood here as claiming that hope must be sacrificed in meeting these other norms. I will argue later that hope is much less often in conflict with other health care provider duties than is commonly assumed (see especially Chapter Seven).

provider is active in “getting the patient to hope.” The health care provider is thereby placed in a position of control over what the patient hopes for, potentially without adequate reflection on what the hope(s) should be based on (given who the patient is) and how one should encourage these.¹² A related problem with this duty is that, as it is commonly discussed in the existing hope literature, the impression is given that the object of hope, i.e., what should be hoped for by patients, is clear, obvious, or unproblematic - all the health care provider has to do is promote it. This impression is false: it is not immediately clear what patients “should” hope for. As I will demonstrate in my analysis of false hope in Chapter Five, many assumptions about “reasonable” or “appropriate” hopes are made by health care providers that need to be questioned, such as what counts as evidence for or against the legitimacy of holding a particular hope.

2.5: Revision of the original duty

Based on the above-described concerns, the duty to promote hope should be revised in such a way that these concerns are addressed and the (moral) complexities of the role of hope in patient care are captured. Accordingly, the new version I have developed states:

¹² I do acknowledge that the duty to promote hope could be read as an open-ended duty whereby hope is promoted by the health care provider engaging the patient and learning about her values in order assist the patient in finding hope. However, this understanding of and approach to the duty to promote hope is not very prominent in the hope literature. This suggests that a new formulation of this duty may be better at encouraging attention to the patient and how who she is relates to what she hopes for.

Health care providers have a responsibility to foster conditions within which patients can discover and continue to have hope.¹³

Adequate justification for this revised claim is provided by the reasons for attending to patient hope discussed above; i.e., the evidence that hope can have positive physical and psychological effects, that health care providers can influence patient hope, and that patients come to the health care system with certain hopes and expectations supports the new formulation. First, the importance of patient hope is acknowledged by making health care providers responsible for not destroying the ability of patients to hope; a minimum condition entailed by the above-described responsibility. Given the potential dangers that accompany health care providers actively promoting hope, this negative responsibility with respect to patient hope establishes an appropriate baseline - patients with hope should not be left without hope after interactions with health care providers. However, an important caveat is required: generally speaking, it is better for patients to have hope than not; hence the minimum expectation that health care providers should not destroy all hope(s). But, when specific hopes held by specific patients are at issue, there may be cases when it is appropriate for a health care provider to “destroy” a particular hope. For example, if a patient hopes that her severed arm can be reattached and the arm is beyond repair, health care providers should not generally preserve this hope. In conjunction with this though, the positive expectation will be that when a particular hope

¹³ A possible revision or addition that one might want to make to this claim of responsibility is that health care providers have a responsibility for fostering conditions within which not only patients, but health care providers themselves, can discover and continue to have hope. This will be discussed further in Chapter Six.

is destroyed, health care providers will suggest an alternative (or alternatives) and assist the patient in working towards being able to hope for something new. The health care providers could, for example, emphasize the new developments in prosthetics and open discussion with the patient about the various possibilities. Second, the positive responsibility to foster conditions for hope recognizes that health care providers can create opportunities for patient hope and should thereby be able to make it more likely that those patients without hope will discover it. These aspects of this responsibility will be discussed in more detail in Chapters Four to Six.

Briefly,¹⁴ the advantages of this new formulation are that:

- (1) It puts the onus on health care providers to be aware of the power of both their words and their actions to shape as well as shatter patient hope, rather than directly or immediately asking them to use that power to *promote* patient hope. Being asked to foster conditions for hope, I will argue (primarily in Chapter Six), should automatically raise questions about hope's role in health care that need to be investigated. For example, what are the "conditions" within which patients can hope? One avenue for answering this question will be to understand how power differentials in health care can affect hope. Discussions of the duty to promote hope are less likely to raise awareness of this.
- (2) It allows room for patients to hope based on their desires for their future - in this formulation, patients are the ones who will discover and continue to have hope within the supportive conditions. This gives patients an active role with respect to their hope and

¹⁴ I will only highlight the main advantages of the new formulation here as Chapters Four to Six will explore these in depth.

helps to emphasize the importance of attending to patients as persons, whose values and beliefs should shape what is hoped for.

(3) It makes both health care providers and patients accountable with respect to hope and thereby fosters a more equal relationship between them - this version allows that everything may be done by health care providers to provide the conditions for hope and to not destroy hope, and that a patient may still not have hope. As the original duty is written, it has not been fulfilled if the patient does not have hope; this has the effect of shifting the responsibility for hope completely away from the person/patient, whose hope is (ought to be) the focus, to the health care provider.

(4) This new formulation should also help to stimulate conversation and thought about the context within which interactions between health care providers and patients take place. Many, if not most, discussions about hope in health care ignore the ways in which social, ideological, cultural, and political forces can impinge on what is assumed or perceived to be possible with respect to hope. The discussions also ignore how these forces can affect the structure and delivery of health care and the effect of these on the ability of patients to hope (see Chapter Six for more).

Two important changes have been made in the new formulation for attending to hope in health care that require further comment: first, there is the shift from speaking of a duty or obligation to that of a responsibility; and, second, there is an emphasis on fostering conditions for hope rather than directly promoting hope. I will explain and defend these changes in order below.

When it is said that a person has a duty or obligation (these terms are usually taken

to be synonymous), this is understood to mean that certain acts “are required, or ought to be done” (O’Neill 1992, 273) by that person; judgements of obligation deal directly with conduct or how persons should behave (paraphrase from Thomas and Waluchow 1998, 13). One’s duty(ies) can arise from being a member of society, holding a certain position or job, and/or having a special relationship with someone, for example, parent-child.

Health care providers are entrusted with the care of persons who are sick; by virtue of being involved in these relationships and having an esteemed position in society, certain obligations are attached to these professions. These duties are sometimes captured under the heading of role responsibility: “This [phrase] refers to the duties (often culturally determined) which are attached to particular professional or societal or (as in the case of parents) biological roles.” (Honderich 1995, 772) To some extent then, responsibility and duty are also taken to be synonymous. Why then am I making it a point to change the language in the reformulation?

My main reason for the shift is not to enforce a rigid distinction between duty and responsibility, but to avoid some of the negative connotations associated with talk of performing duties. Three relevant criticisms of theories of duty are summarized by Onora O’Neill:

One charge is that theories of duty are necessarily individualistic, unable to take account of the social bonds that link agents into communities or of the possibility that certain responsibilities are shared rather than individual. A closely related charge...is that theories of duty, and above all of rights, are relevant only when social relations are antagonistic, and that an ethically superior vision of human life would seek to overcome antagonisms, so making a society of love and virtue possible. A third criticism is that

theories of obligation are blind to the ways in which ethical responses to others may demand feelings and emotions as well as the performance of required acts. (O'Neill 1992, 277)

Each of these criticisms highlight particular difficulties or associations that are made with talk of duties and will be discussed below in order to more fully appreciate the application to hope in health care. (I do not plan to undertake a larger theoretical discussion of theories of duty; I only wish to make use of O'Neill's points as a means of drawing out the difficulties related to my project.)

The first criticism identified by O'Neill charges that duties tend to focus primarily on or are believed to apply only to individuals and that duties are thereby less able to allow for social bonds and shared responsibility. Coordination and communication amongst team members with respect to patient hope would be useful for providing a continuity in "hope care" for each patient and, thus, the responsibility for hope should not fall only to one member of the health care team. Fostering conditions for patient hope should be a shared responsibility amongst all health care providers, as I have indicated in the new formulation. Telling each provider that he or she has a duty to promote hope may help ensure that each attends to hope, but, if duties are thought to apply only to individuals, then it is less likely that the different providers will share and discuss fostering conditions for hope in the way that making it a responsibility might encourage.¹⁵

¹⁵ This raises a possible criticism of having separate codes of ethics for each health care provider group without also having some sense of overarching or overlapping commitments for all working in health care. Even though each code identifies the same or similar guiding principles, these are always cashed out, understandably, in terms of each profession and thereby potentially fail to give a sense of the overall goals of health care or of shared responsibilities.

O'Neill's second criticism suggests that duties and obligations are only necessary when social relations are antagonistic. It is even often suggested in everyday conversation that an undue focus on duties and rights leads to greater divisions between people who "are marking out and defending their territory." Many duties or obligations have corresponding rights; that is, if I have a duty to respect your autonomy, you have a right to non-interference. If there is a duty to promote hope, can a patient say that she has a right to this and that her health care providers "must" provide it? Unlike a right to free speech or a right to privacy for which actions that protect or infringe on these rights have been (fairly adequately) specified, the actions and interactions that can affect hope do not seem to be ones which will *guarantee* either the protection or infringement of a "right to hope." In any case, if duties and obligations are frequently associated with setting up and maintaining boundaries between people, this may not be the most appropriate language to use for guiding patient-health care provider relationships when emotions are the subject. Although, as mentioned above, I am concerned about health care providers, especially physicians, trying to impose their understanding of reasonable or realistic hopes onto patients and I want to guard against this (which implies maintaining some boundary between patients and health care providers), this does not mean that talk of rights or duties with respect to hope will be of most use. What will be of greater use is an increased awareness of the actions and, especially, the interactions that influence hope in conjunction with a stronger sense of accountability for positively and negatively shaping patient hope(s). This awareness, I contend, will be promoted more by the revised responsibility than the original duty. As Claudia Card states,

The point of taking responsibility is often to construct or to improve situations and relationships rather than to control, contain, or dominate. (Card 1996, 23)

The third criticism made by O'Neill emphasizes the importance of attending to feelings and emotions as well as to the performance of required acts. One of the difficulties with Kantian ethics, for example, is that it gives the impression that one must always act "for duty's sake" to the exclusion of emotional ties with others. While this may be a misinterpretation of Kant's theory, the association it makes between performing one's duty and ignoring emotions is something I want to avoid. Thus, talking of a responsibility to think about or to take into consideration another person's feelings and/or to foster conditions within which certain emotions can be expressed seems more appropriate for attending to hope in health care; it helps to emphasize the roles of and relationships between the involved individuals.¹⁶

It is for these reasons then that I have moved from the use of duty to that of responsibility with respect to the stated expectation of health care providers concerning patient hope. As mentioned, one of the main advantages of this reformulation is that it should encourage each health care provider to think about the conditions that influence patient hope and how health care is being delivered (for example, the need for individuality and attention), rather than telling her that she has to promote patient hope (by whatever means possible?) and that the duty is not met if the patient does not have hope. It is wrong to expect health care providers to bear the brunt of the work with respect to patient hope

¹⁶ In Chapter Four, I argue that feminist care ethics is most suited to considering the nature and type of relationships that are formed between individuals, such as patients and health care providers, and how these relationships can affect what is hoped for.

without expecting patients to be involved as well (indeed, they ought to be). Making it a responsibility to foster conditions for hope leaves room for the patient to hope or not to hope. It also allows one to judge that the health care provider did “everything” possible to assist a patient in finding something to hope for, fulfilling the responsibility, even when that patient still does not have hope.

These latter points also apply to the shift in wording from promoting hope to fostering conditions for hope. As should have become clear in the listing of advantages of the new formulation, I contend that an emphasis on fostering conditions for hope is more appropriate - on the grounds that this will help to ensure a more balanced relationship between the health care provider and the patient, assist in allowing the patient to determine or direct what she hopes for, and, promote discussion and attention to the context within which patients and health care providers meet. This recognizes that the influence of social, political, and cultural differences as well as the structure and operation of health care institutions can be assessed with respect to hope.

There is one additional advantage to thinking about fostering conditions for hope that is worth mentioning now, in light of the work to be done in Chapter Three. In Chapter Three I will explore the definition of hope and compare and contrast it with optimism, wishing, hopelessness, fear, and despair. One of the primary outcomes of this analysis will be to demonstrate that hope, or more accurately hoping, is a flexible and dynamic process. It is possible for a person to have, for example, hope for a cure one day and not the next and vice versa. Moreover, rather than thinking of hope and hopelessness on a single or straight continuum, it will become clear that a person can have hope for

something in one part of her life and have no hope about another aspect, without becoming filled with hopelessness. As such, it seems that requiring health care providers to foster conditions for hope will be more able to deal with and respond to these changeable aspects of hope. Promoting hope, as the original duty required, seems too much like a “pat-formula” that can become part of a check-list where one attends to hope in a patient once, the patient has it, and one’s duty is done. The idea I have in mind is similar to the shift in thinking that has taken place with respect to informed consent. It is now stressed that it is informed *choice* that should be sought and that disclosure and decision-making is a process, not a static interaction that takes place once and is completed when the person has signed the release form.

The case should now be made for the shift in terminology from duty to responsibility in the reformulation. We will see in the coming chapters how this reformulation “sets the stage” for thinking about hope’s role in health care.

2.6: Considering the “principle of respect for hope”

Before I end this chapter, it is worth considering another possible revision of the original duty, even though it is one which I have rejected. In their discussion of oncology and hope, Kodish and Post refer at one point to “the principle of respect for hope.” This principle is mentioned in the context of considering how much hope to give patients.

But how and when to introduce facts in given cases is a matter of significant ethical concern, and here the principle of respect for hope must always remain relevant. Oncologists need the freedom to negotiate this sensitive moral terrain...(Kodish and Post 1995, 1818)

A bit of background will help to frame the introduction of this principle. Kodish and Post are writing an article that is, in part, a response to a court case in California, *Arato v. Avedon* (1993). According to Kodish and Post, what was at stake for the physicians in this case was their discretion with respect to the disclosure of statistical details of prognosis. Kodish and Post want to guard against the courts dictating every piece of information that must be given to patients and they firmly maintain that physicians need to have some control over what is told to patients and when. As such, the introduction of the principle of respect for hope is, to my mind, a way of creating a buffer for truth-telling obligations; if physicians (especially oncologists) have to maintain hope in patients, then they should not be forced to disclose details of the prognosis that may have a detrimental effect on patients' emotions. The difficulty I have with this approach to attending to hope is that Kodish and Post seem somewhat more concerned with preserving professional autonomy than with whether the hopes that are promoted take patients' values and beliefs into account. Also, this framing for introducing the principle of respect for hope reinforces the notion that hope and truth-telling are frequently in conflict.¹⁷

Despite my concerns with how Kodish and Post's discussion introduces the "principle of respect for hope," one advantage to this principle is that its wording is familiar in medical ethics and will be familiar to many physicians. For example, respect for autonomy is well-known and leads to a number of actions that are meant to demonstrate this respect, such as ensuring patients make informed choices about their health care. In a

¹⁷ I do not explore this supposed conflict in this work; however, I do discuss it as a future project in Chapter Seven.

parallel fashion then, one might assume that respect for hope will entail certain actions meant to preserve or maintain patient hope. At the very least, respect for hope may be understood to mean that hope should not be destroyed in others - a point in its favour. However, it is unclear whether calling for health care providers to respect hope will have the same effect as calling on them to respect autonomy. A relevant difference between hope and autonomy is that autonomy is central to human identity and freedom in a way that hope is not.¹⁸ The ability to make decisions for oneself and to be recognized as a decision-maker (when one is competent) is critical for being able to live one's life in the manner one chooses; respecting autonomy forms the basis for a number of other responsibilities and rights, such as truth-telling and non-interference. While hope is an important emotion (for reasons already discussed), it is not clear how one should respect hope in other persons or if the use of "respect" will address the concerns I have about how hope is currently conceived in health care; again, one can ask why hope is being picked out as opposed to other emotions or even as opposed to respecting emotions themselves.

The latter point about respecting emotions highlights an additional difficulty with the phrasing of respect for hope - we tend not to talk about emotions in this way. What does it mean to respect an emotion? "Respect for hope" seems important in that it implicitly acknowledges that there may be differences of opinion between the physician and the patient about what can or ought to be hoped for. But when the question of how much hope to promote for patients is addressed by Kodish and Post, little attention is

¹⁸ Even though I will suggest in Chapter Seven that fostering hope is related to supporting autonomy, this point still holds.

given to the patient's experience of the illness, what the values of the patient are, and how what the patient hopes for is or is not connected with her own well-being.

How much hope should the oncologist foster when talking with patients and families? The answer to this question will vary with the type of cancer, the patient's age, underlying medical conditions, and the point in time at which the discussion occurs. (Kodish and Post 1995, 1820)

As evidenced by Kodish and Post, the potential for misinterpretation or misapplication of this principle of respect for hope is as great as the original duty; both the original duty and this principle fail to provide an adequate basis for addressing the role of hope in health care. As such, I am not convinced that advocating for a principle of respect for hope will be an improvement over the reformulation I have proposed.

2.7: Conclusion

This chapter has set the stage for the analyses in the coming chapters. I have presented and assessed the justification for attending to hope in health care concluding that it is important for health care providers to consider patient hope. However, I rejected the claim that health care providers have a "duty to promote hope" in favour of a reformulation, namely that health care providers have a responsibility to foster conditions within which patients can discover and continue to have hope. While Chapters Four, Five, and Six discuss in detail the application of this responsibility to specific situations that arise in health care, such as false hope, and how it will operate in a variety of clinical contexts, this discussion cannot proceed without a clearer understanding of what hope is. Accordingly, I now turn to Chapter Three for the definition and conceptualization of hope.

Chapter Three

Defining and Conceptualizing Hope

"I'd rather have hope than be able to define it"

Joseph J. Godfrey, A Philosophy of Human Hope

3.1: Introduction

In the previous chapter, I demonstrated that hope has an important role in health care; it not only has some healing properties, but is a fundamental aspect of what health care is all about. That is, patients have certain hopes, fears, and expectations about their clinical encounters, as do health care providers, and these need to be addressed. As such, I argued that attending to hope in health care should be a matter of fostering conditions within which patients can discover and continue to have hope. Throughout that discussion though, I took it to be apparent what hope is - an agreed-upon definition of hope in health care is not essential for making the argument that the obligation to maintain hope in patients needs to be revised. However, before I can continue examining such things as false hope and make suggestions for fostering the appropriate conditions for hope, the definition and conceptualization of hope that supports this project needs to be established.

"Hope" is a word used frequently in our language; it can function as a noun and as a verb. While many of us would say that we have had hopes in the past, or currently hope for particular things, or that we are hopeful in general about the future, actually describing what hope is is rather difficult. The task of explanation may become even more difficult if you further tried to describe how a person who is seriously ill/injured or who has a chronic

illness can hope and what this hope may consist of. As indicated in the Introduction (Chapter One), my aim in this chapter is to develop a new definition of hope - specifically one that works in the context of health care - and I will undertake this “defining” investigation primarily via considerations of individuals who are ill, suffering, and hurt.¹ Remember the key boundaries established earlier for this new definition: (1) the focus is primarily on hope from the (adult) patient’s perspective in four clinical contexts; patient stories will be utilized to guide and shape our intuitions with respect to hope in these situations; (2) the task is not to describe the necessary and sufficient conditions for all uses of “hope,” but to identify: a) the aspects of hope that are common to most understandings of hope, especially those in health care and b) the aspects of hope that are unique or of particular importance for patients and their experiences of illness or injury and thereby need to be emphasized in the new definition; and, (3) this definition should fit with and help illuminate ethical debates about the role of hope in health care. Thus, I will not attempt to deal with all possible philosophical issues that may arise when one considers hope or to address all possible uses of the term “hope,” but will cover those aspects of hope that are relevant to the described parameters of illness and health from the patient’s perspective.

3.2: Problems with an Initial Definition

A useful place to start in attempting to get a better sense of what people mean (or

¹ Of course, if the definition that I do develop will work in a broader range of situations than I consider in this dissertation, this will be a definite advantage. I make no claims that it will.

likely mean) when they refer to “hope” in health care will be with the dictionary definition of hope. Webster’s Dictionary (1989) defines hope as “desire accompanied by expectation of or belief in fulfilment.” While it is true that desire, or a person’s desires, are part of hope, a survey of the hope literature suggests that this definition is unsatisfactory in at least two respects. First, the types of desires that are typically involved in hopes are restricted by the values a person holds and her relative ranking of these values. The Webster’s definition leaves the desires that can count for hope too open in this respect as it is not just any desire that can form the basis of a hope. One does not have a hope for every desire that one expects to be fulfilled; one could instead be relatively indifferent about it. For example, although I may be hungry and know the orderly will be bringing the food trays at some point (leading me to expect that my hunger can be met), it may not matter whether I eat now or in a few hours based on my interest in when I will be discharged from the hospital (I hope it will be soon).

Second, the qualification of desires this definition does give - expectation of fulfilment - is, in another sense, too strong and unnecessarily restricts what can be hoped for. Many definitions of hope only require that the object of a hope, what is desired, be probable (fifty percent or greater) or likely to come about, while others are even less stringent requiring only that what is desired be possible. Further, the association of hope with some calculation of the likelihood of the hope being realized is disputable. Discussion of the probabilities of a hope often will only come up when one’s hope is challenged by another as being unrealistic; for example, probabilities may be used as a means of justification for holding on to the hope or contesting what is hoped for. Another way of

expressing this criticism is to say that this definition of hope does not adequately emphasize the element of uncertainty that often accompanies what is hoped for (this is of particular significance in health care in terms of, for example, prognosis for recovery from a serious brain injury). Hence, expecting that one's hope will be fulfilled is too strongly phrased and seems to imply that one can only hope for something if it is relatively certain that this hope will be met. While a person may want the hope to come true, the reason the person is *hoping* that it will (rather than *believing* it will) is that the future is uncertain.

Thus, two features that should be part of a definition of hope are already identified: one, the uncertainty of the event hoped for will need to be explained and highlighted and, two, the types of desires that form the basis of hopes will need to be clarified. I next turn to an examination of selected historical, philosophical accounts of hope to determine what these philosophers say about hope and why. These accounts will provide additional insight into what hope is or should be; at the least, a sense of the helpfulness of these accounts for developing an understanding of the role of hope in health care will be gained.

3.3: Historical Accounts of Hope

This section will focus, in particular, on the writings of Descartes, Hume, Hobbes, and Aquinas. While other theorists have also discussed hope, I do not endeavour to undertake a comprehensive nor exhaustive recounting of all historical descriptions of hope. The four named philosophers have been chosen because they cover a broad range of philosophical commitments and, as expected, there are some divergences in the definitions of hope provided. It is through an analysis of these definitions and their similarities and

differences that a better sense of what features of hope are important will be gained as well as what features may be of particular importance for considerations of hope in health care. Ultimately, I argue that Aquinas offers the most useful discussion of hope and its conditions.

Each of the four philosophers discusses hope as one of the human passions or emotions. Often, hope is described as part of a listing of various related passions and is compared to them; these various passions include joy, sorrow/grief, fear, and despair. Thus, how hope is understood by these philosophers is rounded out by including the comparisons made between hope and the related passions. In the final two sections of this chapter, I will discuss the relation of hope to wishing and optimism as well as explore the opposites of hope - the comparisons made here will set the stage for these sections. Out of the four philosophers, Aquinas spends the most time on hope as he is interested in making the case for hope as a moral virtue. Yet, Hume, Hobbes, and Descartes each have something to offer: the small variations in the phrasing of hope's conditions, for example, suggest different ways of interpreting the role of uncertainty in hope.

In *A Treatise of Human Nature*, Hume (1888) describes hope as one of the direct passions. For Hume, the direct passions are those that "arise immediately from good or evil, from pain or pleasure" (276) and include desire and aversion; joy and sorrow; and, fear and hope. The following characterization of the latter four direct passions is given by Hume:

When good is certain or probable, it produces JOY. When evil is in the same situation there arises GRIEF or SORROW. When either good or evil is uncertain, it gives

rise to FEAR or HOPE, according to the degrees of uncertainty on the one side or the other. (Hume 1888, 439)

Hume further describes how uncertainty, in terms of the individual's estimation of the good or evil being realized, plays a role in whether a person has fear or hope.

Suppose, then, that the object, concerning whose reality we are doubtful, is an object either of desire or aversion, 'tis evident, that, according as the mind turns itself either to the one side or the other, it must feel a momentary impression of joy or sorrow. (Hume 1888, 440)

According as the probability inclines to good or evil, the passion of joy or sorrow predominates in the composition: Because the nature of probability is to cast a superior number of views or chances on one side; or, which is the same thing, a superior number of returns of one passion; or since the dispers'd passions are collected into one, a superior degree of that passion. That is, in other words, the grief and joy being intermingled with each other, by means of the contrary views of the imagination, produce by their union the passions of hope and fear. (Hume 1888, 441)

From these passages, we learn that Hume places the two passions of fear and hope on a continuum of probability of fulfillment between the two "certain" passions of grief and joy, respectively. If the good (or pleasure) seems likely to come about, a person will have hope for that good whereas if the good is certain, the person will experience joy. Likewise, if the evil is certain, the person feels sorrow or grief, and, if the evil seems likely, the person will feel fear. Hope therefore has two conditions on Hume's account: first, what is hoped for is considered to be good (or a good); and, second, the good is uncertain, but seems likely to be reached or achieved. Given that Hume describes hope as a mix of joy and sorrow, it seems that a person can only have hope when the prospects for joy (when the evidence appears to the individual to be in favour of the good being achieved) outweigh

the prospects for sorrow (when the evidence appears to be against the good being achieved). On one reading then, for a person to have hope, what is hoped for will have to be judged (by that person) to have a probability of fifty-percent or greater of being achieved, such that the joy outweighs the sorrow in the mix.

For Hume, individuals are drawn towards what is believed to be good/pleasurable and tend to shy away from what is believed to be evil/painful (see Hume 1888, 438). Thus, implicit in this definition of hope is the person-relative nature of this passion; i.e., the person with hope judges something to be good and this person believes that there is a greater chance of this good being achieved than not. The first condition for hope can therefore be rewritten to claim that what is hoped for is considered to be good by the individual with that hope; in other words, the person desires what is hoped for. As discussed in the previous section, this condition is correct – if a person does not desire or want what is anticipated, then it seems that this person is not actually hoping for that event or state of affairs.

However, Hume's second condition for hope is problematic for two reasons, especially if the reading given above with respect to probability holds. First, it conflicts with the apparent fact that persons are properly said to hope for things that have a low probability of being achieved. For example, it seems right to say that Bonnie can hope to walk again unassisted, even though this hope has a very low chance of being realized given the severity of her second stroke. This unnecessary restriction of what can be hoped for based on a favourable probability calculation was also identified above with the dictionary definition. Second, if Hume can be read as suggesting that persons undertake something

like probability calculations, the recognition of “an opposition of contrary chances or causes” (Hume 1888, 440), and it is only via the weighing up or summing of these contrary chances of the object being realized or not that one can arrive at hope, then this does not seem right. It is questionable whether people actually need to (or do) undertake a full consideration of the evidence for and against what is desired being realized as part of arriving at a particular hope. It is more likely that if the possibility that the hope will or could be achieved, generally speaking, exists (what is hoped for is not impossible nor inevitable), then that person can hope for that state of affairs. Although Hume does acknowledge that “probability [is] a wavering and unconstant method of surveying an object” (Hume 1888, 444), the passages cited above seem to make it the case that probability assessments are a necessary part of hope (and fear).

There is one possible response Hume could make to my criticism of probability as a condition of hope and it casts doubt on the reading given above of Hume’s analysis of hope. This response is found in the context of an example about an evil that is only slightly possible, but is still able to cause fear in the individual.

We find that an evil, barely conceiv’d as *possible*, does sometimes produce fear; especially if the evil be very great. A man cannot think of excessive pains and tortures without trembling, if he be in the least danger of suffering them. The smallness of the probability is compensated by the greatness of the evil; and the sensation is equally lively, as if the evil were more probable. (Hume 1888, 444)

In other words, Hume does acknowledge that there are situations where the *magnitude* of the pain or evil is so great that a person may experience fear that does not correspond with the likelihood of that pain being inflicted. While Hume seems to regard these fears, or

causes of fear, as somewhat uncommon experiences, he does recognize these exceptions to his general description of fear and the role of one's subjective probability estimates for this passion.

Hume does not mention whether the same "exception to the rule" could also be true of hope, i.e., that if what is desired by a person is very important to that person, the person may hope for it, even if it only has a small possibility of being achieved. It does seem that this parallel case could be made for hope. For example, many patients with terminal illnesses do hope to live to see their child's birthday, given that it is of great importance to them (both the child and the parent), even though the possibility of living that long may be quite low. Alternatively, as another exception to the rule, a person may sometimes hope strongly for a state of affairs that is less important to her given that it may be more likely to be realized, and it permits this individual to not have to face the possibility that what is most important to her may not be achievable. By focusing more on the hope that can likely be realized (for example, the hope that one will be able to take a step today in physiotherapy), a person may be able to hold onto a further, more important, hope that has a lower possibility (for example, the hope that one will be able to walk again unassisted).² When the more likely hope is realized, this can help the person in sustaining her hope for the more distant, desired state of affairs. While this response I have attributed to Hume alleviates some of my concern about needing a favourable probability estimate

² This exception to the rule helps to establish one way in which individuals may be vulnerable with respect to what they hope for. If the probability is low that what is desired most will be fulfilled, the person may be cautious about admitting that she has this hope as, for example, negative feedback from others could destroy this hope. The connection between hope and vulnerability will be explored in depth in Chapter Four.

for hope, this response does not address my deeper concern with making hopes that have a low chance of being fulfilled “exceptions to the rule.” I do not want to limit “legitimate” hopes to those that have a relatively good chance of being realized.³ Thus, Hume’s definition of hope is unsatisfactory in important respects, similar to the dictionary definition discussed above. However, by undertaking this analysis of possible readings of and exceptions to Hume’s definition of hope, it has been demonstrated that the importance of what is hoped for by a person is a key aspect of whether that person has hope - what hangs on the hope, as judged by the person hoping, should not be overlooked.⁴ This aspect of hope is picked up in both the new definition (see Section 3.5) and in the following chapters.

One final point about Hume’s definition is that since hope is the result of a mix of joy and sorrow, it is likely that the person with hope knows that the situation may not turn out as her “estimate” suggests. In other words, the person with hope is aware (on some level) that her hope may not be realized. Thus, Hume’s account helps to establish that hope is reality-based and that being hopeful does not necessarily lead to the person ignoring a potential bad outcome. In the final two sections of this chapter, when hope is compared to wishing and optimism as well as the opposite emotions of despair and fear,

³ This will become important in Chapter Five where I discuss the grounds upon which hopes can be contested.

⁴ This point, suggested by Hume’s writing, indicates that there are two scales with respect to hope: one, a scale of probability that measures the uncertainty of what is hoped for and, two, a scale of the “goodness” of the hope in terms of what hangs on the hope or how much the person wants the hope to come about. Aquinas identifies these two scales more clearly in his writing – see further comments later in this section.

this grounding in reality will be utilized as a distinguishing feature of hope.

Next, I turn to Descartes, since he also places hope on a continuum between other passions.

We are prompted to desire the acquisition of a good or avoidance of an evil simply if we think it possible to acquire the good or avoid the evil. But when we go beyond this and consider whether there is much or little prospect of our getting what we desire, then whatever points to the former excites hope in us, and whatever points to the latter excites anxiety...When hope is extreme, it changes its nature and is called 'confidence' or 'assurance' just as, on the other hand, extreme anxiety becomes despair. (Cottingham, Stoothoff, and Murdoch 1985, 350-351)

This definition of hope is reminiscent of the one provided by Hume. Again, it seems that hopes must be reasonably certain (probable) in order for the person to actually experience hope - "much prospect of getting what we desire...excites hope." The same criticism made of Hume and the dictionary definition with respect to probability judgements can thereby be made here as well. Thus far then, not much new is gained by this investigation into Descartes' analysis of hope, but we are not yet finished with Descartes.

A slightly different definition of hope is given later in Descartes' discussion of the specific passions – one that revises this probability condition and leaves it more open.

Hope is a disposition of the soul to be convinced that what it desires will come about. It is caused by a particular movement of the spirits, consisting of the movement of joy mixed with that of desire. (Cottingham, Stoothoff, and Murdoch 1985, 389)

What distinguishes this definition from Hume's is that Descartes claims here that hope is a "disposition to be convinced" – the person is leaning towards believing that what she

desires will come about. This is a weaker condition than that postulated by Hume (at least on the initial reading of his analysis of hope) and makes it more clear that it is the individual's subjective assessment of the likelihood of what is desired being achieved that leads to the hope. When a person is disposed to believe that what is desired will come about, the appropriate mixture of joy and desire is achieved, resulting in hope. Further, as Descartes moves from the related passions of hope, anxiety, jealousy, confidence, and despair to discuss, as a group, irresolution, courage, boldness, emulation, timidity, and terror, he makes the following comments:

...we may hope and fear, even though the expected outcome does not depend on us at all. But when we think of it as dependent on us we may have some difficulty in deciding upon the means or in putting them into effect. This first difficulty leads to irresolution... (Cottingham, Stoothoff, and Murdoch 1985, 350)

What I want to draw attention to here is the suggestion by Descartes that a person can hope for something, be inclined to believe it will obtain, even if the outcome does not depend on herself. In other words, Descartes suggests that having hope does not depend on whether its being fulfilled is achieved by one's own actions or those of someone else. Descartes also says that a person can hope for something that is beyond anyone's control (for example, such as in cases of spontaneous nerve regeneration which enables a person who is quadriplegic to regain some motor function).

Descartes does not discuss whether any expectations or responsibilities accompany those occasions when a person's hope is dependent on the performance of certain actions by others. Does the person upon whom another's hope is placed have a responsibility to

undertake actions to help that hope be fulfilled? What would be the justification for this responsibility? This analysis of Descartes thereby flags an important issue to discuss with respect to hope and a person's inclination to be convinced that her hope is likely to obtain - if one needs to depend on factors out of one's control or on other persons for a hope to be realized, both what these factors are and who the other persons are could affect *whether* something is hoped for. *What* is hoped for could also be affected. I will take up these questions in later chapters (see in particular Chapters Five and Six).

Although Hobbes does not say much about hope, a short look at his definition is useful for its phrasing of the possibility/uncertainty aspect of hope. In his listing of the passions of man, Hobbes describes hope, despair, and fear together.

For *Appetite* with an opinion of obtaining, is called HOPE.
The same, without such an opinion, DESPAIRE. *Aversion*,
with opinion of *Hurt* from the object, FEARE.⁵ (Hobbes
1651, 123)

From this brief description, it seems that Hobbes understands hope to involve two conditions, namely that the person desires what is hoped for and believes that it will be fulfilled. This description is similar to that of both Hume and Descartes, but Hobbes does not expressly incorporate a (formal) judgement of the probability or uncertainty of what is hoped for, only that the person believes that it can be achieved. Hobbes does not further fill out what this "opinion of obtaining" is or should be based on. How one interprets this phrase will make a difference to whether a person can be said to properly hope for something that has a low likelihood of being achieved. Conversely, it seems that there

⁵ Appetite and aversion are meant in terms of attraction to a good and repulsion from an evil.

could be a substantial amount of evidence in favour of what is desired, but that a person may still be of the opinion that this desire will not be fulfilled and, thereby, this person may despair, rather than hope.

The advantage of Hobbes' definition of hope is that it does not place hope and despair or fear on a continuum based on the evidence for or against whether what is desired can be achieved (or avoided in the case of fear). An interpretation of Hobbes that allows the individual's subjective reading of the uncertainty of what is desired being realized to be the measure of whether there is hope entails that a strong desire with a small possibility of fulfillment can combine to create hope (much as Hume's exception, noted above). In other words, Hobbes's definition of hope suggests a weaker, yet more plausible, phrasing for the inclusion of uncertainty as part of hope. This weaker condition will be found in the new definition of hope arrived at in Section 3.5.

We now move to the final historical account of hope to be examined. Aquinas assesses hope during his discussion of feeling(s) in the *Summa Theologiae* and compares hope to despair and fear.

...hoping, attracted to the difficult because of its goodness, is opposed to despairing, which shuns good because of its difficulty...yet hoping and feeling afraid are also opposed because they are responses to antithetic objects, good and bad. (McDermott 1989, 202)

Immediately, one can appreciate how Aquinas has captured the two different scales that operate in hope - the scale of probability/uncertainty and the scale of the goodness/desirability with respect to what is hoped for - with his phrase, "attracted to the difficult because of its goodness." Aquinas implicitly acknowledges that a person may

have hope due to the likelihood of something coming to pass, but also that, even if the chance for a certain desired state of affairs is small, the person may still have hope if it is of significance to her. It is important to recognize the involvement of these two different scales in hope as it is often suggested, for example, that if a patient really understood the “numbers” (prognosis) for her illness then she would no longer hold onto the false hope for cure. I contend that this claim misunderstands or ignores the desirability scale that may be operating in this patient’s hope. (I will continue this discussion in Chapter Five.)

Overall, Aquinas’s comparison between the passions of hope, despair, and fear generally agrees with that offered by Hume, Hobbes, and Descartes. Yet, Aquinas’s emphasis on the *difficulty* of obtaining what is hoped for, instead of its uncertainty, highlights two different ways in which the possibility of a hope being achieved can be understood: (1) whether what is hoped for is logically, causally, etc. possible; and, (2) whether what is hoped for is possible in terms of how much work will be required by the individual and/or others to help realize the hope. This spin on the uncertainty or difficulty associated with hope is further expressed by Aquinas in the following: “Hoping adds to desiring a certain buoyancy of spirit in pursuit of what is good but arduous.” (McDermott 1989, 203) I like this description of hope - its addition of a “buoyancy of spirit” - as it conveys both the feeling a person has when she has hope (it is often described as being uplifting, pleasurable, inspiring) as well as the likelihood that a person with hope will often pursue, work towards, the hope being realized to the extent that this is possible.

Aquinas also gives a more formal description of hope:

What we hope for has four distinguishing characteristics: it is good (not bad, like what we fear), future (not present, like what we take pleasure in), challenging and hard to achieve (for hope is an aggressive emotion,⁶ not simply an affection for a future good, like desire), nevertheless able to be achieved (not unachievable, like what we despair of)...So hope is movement of our appetite towards what we perceive as a good difficult, but possible, to achieve in the future. (McDermott 1989, 215)

The first condition for hope - that it is good - captures the sense that what is desired by the person is perceived to be good, something that one should move towards or attempt to preserve. This is the same condition specified for hope by the previous three philosophers and the dictionary definition. The second condition - that what is hoped for be in the future - has not been expressly mentioned by any of the previous accounts, but is generally assumed in the discussion of uncertainty and probability calculations. It is true that many of our hopes concern the future or future states of affairs. For example, Kay makes the following comments about new research into possible abnormalities identified in the brain structure of some persons with manic-depressive illness:

The odds were very strong, however, that the UBOs [high concentrations of water in the brains of bipolar persons indicating potentially abnormal tissue] meant *something*. In a strange way, though, after reading through a long series of studies, I ended up more reassured and less frightened. The very fact that the science was moving so quickly had a way of generating hope, and, if the changes in the brain structure did turn out to be meaningful, I was glad that first-class researchers were studying them. Without science, there would be no such hope. No hope at all. (Jamison 1996, 198)

⁶ An aggressive emotion is defined by Aquinas in the following way: “Sometimes however taking pleasure in something or avoiding pain from it is not within our immediate power and requires effort. To deal with such difficulties we are endowed with emotions that respond to challenges...so-called aggressive emotions.” (McDermott 1989, 201)

The hope is that as science progresses, new cures, treatments, and strategies for coping with mental illness (as well as other illnesses or injuries) will be discovered and the future will be better. This hope is shared by a number of patients and health care providers.

However, there are also hopes that are not necessarily future-directed, but are based primarily on a lack of information or knowledge. For example, a patient may hope her biopsy tests come back negative for malignant cancer (she can still hope for this even if her physician knows what the results are). While she may have to wait for these results, the key basis for this hope is the current paucity of information about her medical condition. Another way to state this is that her knowledge about the test results is in the future and that she can thereby presently hope for negative results. It is also possible for people to have hopes about the past. For example, a person who is adopted may hope that her birth was not the result of a sexual assault. That a hope be future-directed seems an unnecessary restriction by Aquinas and is not one I will employ.

The third condition described by Aquinas - that what is hoped for be challenging or hard to achieve - has already been discussed above, but warrants further comment. This condition is too narrow to include all hopes; for example, it seems to rule out those hopes that depend on things out of the control of individuals, such as the hope that one does not carry the gene for Huntington's disease. However, this condition does give one possible explanation as to why it is sometimes hard for an individual to hold onto a particular hope: If there is little the person can do to help realize her hope and/or what can be done is very demanding or taxing on the person (or on others), this individual may not be able to sustain her hope. It seems important not to lose this insight into what is hoped for as it

gives rise, again, to questions about what the responsibilities of others, including health care providers, should be with respect to patient hope - what are the ways in which a patient's ability to hope can be bolstered when what is hoped for is hard to achieve?

The fourth condition - that what is hoped for be achievable - denotes the possibility aspect of hope. In one sense, this condition is more lax than was found in Hume's and Descartes' accounts of hope as all that Aquinas requires for a person to have a hope is that what is hoped for be possible, i.e., what is hoped for does not have to be probable. But, this condition does place a restriction on what it means for a hope to be possible or achievable - the hope has to be possible with respect to the actions of oneself or others.

What makes things possible is power, either our own or someone else's. We hope in both cases, but in the latter we also expect, looking not only to the good we hope to achieve but also to the agency by which we hope to achieve it...what makes things objects of hope is not possibility as a mode which qualifies the way predicates are true of their subjects, but possibility as being within someone's capacity. (McDermott 1989, 215)

This condition of "power of achievability" clearly connects with his third condition and the same criticism can be made here as well - Aquinas is unduly restricting what can count for hopes. While I appreciate the fact that Aquinas wants to stress the role of the individual in hope and in what is hoped for, I do want to allow that persons can hope for states of affairs that are (or at least seem to be) out of any particular person's power to realize. It may be that it is more difficult to sustain hopes that are not under, or potentially under, someone's control, but I do not believe that this makes it impossible to hope for such

things.⁷

However, despite my concern about the narrowness of these latter two conditions, some further comments by Aquinas about the “resources” a person has for hope are worth quoting at length.

Despair and hope both presuppose desire, because unless we desire something we can neither hope for it nor despair of it. You can cause hope by making something achievable or by causing it to be thought achievable. Riches, courage, and experience all make us more capable and give us hope; instruction, persuasion, and (again) experience can change our assessments of our capabilities (generating hope or, sometimes, the reverse). Inexperience can also generate hope, in the same way that experience can kill it: young people hope easily because they are intent on the future, high-spirited and prepared for challenge, and because they are inexperienced enough to think everything possible...Sometimes it is not we ourselves who have the capacity to make something possible but someone helps us. So hope has two objects: what we hope for...and what makes it possible...Perception of difficulty alerts us and perception of achievability quickens our efforts; so hope inspires us to apply ourselves to action and to enjoy it.
(McDermott 1989, 215-216)

Aquinas makes a number of points in this passage related to the possibility of hope. He identifies some of the resources that may assist the (perceived) achievability of a hope - riches, courage, experience, age, instruction, and persuasion. The capacities of oneself and of others are both relevant to hope and, importantly, Aquinas points out that one’s past experiences and, even, lack of experience can all factor into whether one is likely to hope

⁷ Although I allow here that patients may hope for things that are not immediately within someone’s power to effect, I would argue that many of the hopes patients have can motivate action(s) on the part the individual and by others. Actions by others can include those that assist in sustaining or supporting a patient’s hope, but may not be directly related to whether that hope is realized.

or to despair. The role of others in shaping our assessments of whether a future state of affairs is achievable is acknowledged and this is one of the key aspects in considering what the role of health care providers should be with respect to patient hope - how are these assessments made? On what grounds? Does the position a person has influence her ability to persuade others to hope or to not hope? Some articles on hope have suggested that the availability and extent of internal and external resources does affect whether a person is able to hope or sustain hope (see Dufault and Martocchio 1985; Farran, Herth, and Popovich 1995). We see here that Aquinas has already recognized that the context or situation within which a person is hoping or trying to hope makes a difference to whether that hope can be maintained. This lays the groundwork for the approach to patient hope I develop in Section 3.5 and in Chapter Four.

Via this examination of four philosophical accounts of hope, a number of features of hope have been identified and questioned. All four philosophers agree that what is hoped for is both desired and judged to be good by the individual. It is also agreed that there is an element of uncertainty in hope; yet, there is little consensus as to how this uncertainty or possibility should factor in. I have argued that definitions of hope which require the individual to undertake a detailed weighing of the probability and/or require a relatively high likelihood of success are flawed. It seems a better argument can be made for accepting that hopes with a low chance of being achieved are still hopes. The importance of what is hoped for, according to the person hoping, needs to be addressed as do the “resources” available for hope, especially as we consider the role of hope in health care and the corresponding role of health care providers. Further insight is gained into

how to ensure that the *person* with hope – the patient - is kept at the forefront of this analysis of hope in the following section.

3.4: Considering Muyskens' Definition of Hope

More recent philosophical work on hope has been done from a phenomenological perspective; Gabriel Marcel's work is perhaps the best known of these accounts. Two of his most significant works on hope include: "Homo Viator: Introduction to a Metaphysic of Hope" (1962) and "Desire and Hope" (1963). Marcel relies on his own experiences and prototypical cases of hope to develop a phenomenological account of this emotion and appeals to the readers' experiences of hope for assessing whether he has "got it right." His discussion frequently focuses on illness and captivity as these are seen by Marcel (and by many others) as central human experiences with respect to hope. One example Marcel uses is: "I am bed-ridden by an illness which might paralyze me for life. I hope for the freedom of movement which would come with a restoration of health." Other cases involve being in a Nazi concentration camp or being separated from one's family.

Ultimately, though, Marcel's work moves in a direction away from the issues I want to address in this dissertation, i.e., Marcel utilizes the prototypical cases to work towards understanding hope in a Christian context and argues that God is the ultimate source for our hopes.⁸ While I appreciate that there is, for many persons, a spiritual

⁸ This is only a "thumbnail" sketch of a very complex series of works by Marcel on hope. Although Muyskens also undertakes an analysis of hope within Christianity, I find his initial discussion of hope (the first three chapters of his book) to be quite helpful and more clearly applicable to the secular work being undertaken in this dissertation.

component to hope or to the ability to hope, I do not intend to explore hope from a theological perspective; instead, I situate my investigation in “secular” bioethics. Accordingly, I have made the decision not to pursue Marcel’s work on hope any further and will use the work of James Muyskens, which draws heavily on Marcel’s writing. I believe Muyskens captures a number of Marcel’s main points and attempts to combine these phenomenological aspects of hope with an analytical approach. In other words, Muyskens undertakes both an analytical and phenomenological analysis of hope and ultimately blends the necessary conditions of hope he identifies with “the lived experiences of hope.”⁹ The resulting definition of hope Muyskens arrives at is:

A person hopes that p (where p is a substitute for any proposition or event hoped for) = keeping his life open or fluid with respect to p-where (a) neither p nor not-p is certain for him, (b) he wants p and (c) he sees p as constructively connected with his own well-being and/or concept of himself as a person. (Muyskens 1979, 36)

This definition “adds life” to the conceptualization of hope, both literally and figuratively, in a way the historical accounts do not. Muyskens makes it clear that, in order to adequately attend to patient hope, health care providers must first have a sense of who each patient is as a person, what is of value to her/him, and how the current illness or injury is, perhaps, posing a challenge to that patient’s sense of self and ability to cope. As Nekolaichuk, Jevne, and Maguire (1999) argue: “Frameworks [for hope] that mask personal experience seem to widen the gap between theory and clinical practice...” (592) Connecting what hope is or is defined as to the everyday experiences of patients and

⁹ Muyskens also draws upon the work of Hume, Descartes, Hobbes, and Aquinas in his analytical discussion of hope.

health care providers is critical if health care providers are expected to foster conditions for patient hope. Since Muyskens' definition is able to explicitly draw in the personal nature of hope, a number of elements of this definition will be incorporated into the new conception of hope developed below (see Section 3.5).

In his analysis, Muyskens contends his definition makes four main claims about hope: (1) that the person hoping wants what is hoped for to come about (S wants or desires p); (2) that it is uncertain whether what is hoped for will come about; (3) that what is hoped for is intimately connected to who the person is and what is of importance to her; and, (4) that the person who has hope will be disposed to act in a manner consistent with what is hoped for. In the following, each of these claims will be explained and evaluated; however, conditions (1) and (2) are very similar to what has been discussed in the previous section and, as such, I will spend little time reviewing them.¹⁰

(1) The person wants what is hoped for (S desires that p). The simple point made by this claim, the same one identified by the dictionary definition and the historical accounts, is that a critical component of hope is desire. Hope cannot exist without the individual wanting some thing or some state of affairs to come about. If a person hopes for something, then he or she must desire it or want it to be the case. Desires and, therefore, hopes are person-relative and subjective.

(2) It is uncertain whether what is hoped for will come about (neither p nor not-p is certain for S). As discussed earlier in this chapter, the uncertainty about whether one's

¹⁰ The explanation of each point will rely heavily on Chapter One, "The Structure of Hope," in Muyskens' book; see Muyskens 1979, 7-19.

desire will be fulfilled is often included in other accounts of hope as a probability calculation, i.e., “p is probable” is a condition of hope. Muyskens acknowledges the uncertainty that accompanies hope and allows a weaker condition to serve - what is hoped for only needs to be uncertain. This implies that the only limit on p is that it can not be believed/deemed impossible nor inevitable (another restriction for p is given by condition (3)). Muyskens therefore captures the sense that when a person hopes, she has a certain vision of what she would like to happen (or not) in the future and, thus, hopes she can move from this present to that desired future. In a sense, it is simply the possibility that things could be different from what they currently are if one is hoping to recover from a serious illness or injury, i.e., the uncertainty and unknownness that surrounds the future, that enables a person to hope. Alternatively, for a person with a chronic or mental illness that is currently stable, the hope may be that things stay the same in the future, but this “wanted” future is uncertain, since one’s condition could get worse. There does not have to be a more complex belief (such as a probability calculation) than this for the person to hope.

(3) The person sees p as constructively connected with her own well-being and/or concept of herself as a person. This condition places a restriction on the desires or wants that can properly function for hope; it thereby meets (or attempts to meet) one of the difficulties cited above with the Webster’s definition. Not everything that is desired, and that is considered neither impossible nor inevitable, can be hoped for. As Muyskens says, “One can long, or wish, for something that she knows is not preferred on balance. But one does not hope for such a thing.” (Muyskens 1979, 18) Muyskens provides an example to

demonstrate this claim; I present it here in slightly modified form. Cindy is a former smoker, who has not smoked in the last year, but she has a strong desire to smoke again. She knows that cigarettes are addictive and pose a threat to her health. Cindy's desire for a cigarette conflicts with her overall plan and commitment to living a healthy lifestyle. So, Cindy's desire for a cigarette is not preferred on balance, i.e., it does not outweigh other important values or desires that Cindy has, and, in addition, is incompatible with her desire to be healthy. It seems clear that while Cindy can say she longs for a cigarette, she cannot say that she hopes for a cigarette (and use the term correctly).

While this example makes sense and helps to convey the type of restriction on desires Muyskens is establishing, I am reluctant to endorse this condition without further evidence for it. As it stands, Muyskens' discussion conveys the impression that determining what is in one's well-being or corresponds with one's concept of oneself is relatively easy or unproblematic. It is my contention that this impression is false; for example, there are a multiplicity of ways in which well-being can be both understood and evaluated. Muyskens does allow that a person could be wrong about what is in her well-being or is connected to her concept of herself as a person, but I am unsure as to what this condition for hope asks of people in order for them to properly say that they hope for something. Further, Muyskens suggests that an individual's assessment of what is in her well-being and her concept of herself as a person are, or can be, equivalent - this is not necessarily the case and creates another difficulty for this condition. In order to convince the reader that this is a useful condition for hope, Muyskens needs to say more about how the concept of oneself and/or well-being is to be fleshed out. In the absence of this

explanation, I will argue that a less strong condition will suffice for limiting the desires that are relevant for the hopes of patients.¹¹ (See Section 3.5, condition b.)

(4) The hoping person will be disposed to act in a particular manner, i.e., the person keeps his life open or fluid with respect to p. As discussed by Muyskens, there are two ways in which this aspect of hope can be understood; these will be explained below, but it should be noted that it is not apparent from Muyskens' work which interpretation he actually supports.¹² The first interpretation, the stronger one, claims that the person who hopes is disposed to act as if what is hoped for has already come about.

Consider that an agent who hopes acts in large part like a person who actually believes that the object of his hopes is real. Hoping for something involves practical consequences and entails certain actions or dispositions to act. One who hopes for p arranges his life and emotions as if p were the case. (Muyskens 1979, 14)

As I understand it, Muyskens takes these actions (arranging one's life and emotions as if p were the case) to be indicators of keeping one's life "fluid" with respect to hope as they will increase the chances that the hope will obtain. A person is ready to take advantage of any opportunities that come along that may assist in this, since one is in large part already acting as if the hope had been reached.

¹¹ One of the difficulties I have here is knowing that the weaker condition I endorse may allow some more trivial desires to count as hopes. However, I am willing to accept this to avoid the danger of extending my definition of hope beyond what I can defend. I do not have the space in this project, for example, to work through various conceptions of well-being and how different people will understand or employ this condition for hope.

¹² Although the definition at the beginning of this section I have quoted for hope utilizes the "weaker" understanding of (4), Muyskens, in his previous chapter (Chapter One), puts forth the "stronger" condition as one of the necessary conditions of hope.

While it may be true that hoping for something tends to be associated with acting in certain ways, this interpretation of the link between hope and action seems to be much too strong. If a person is already acting as if the hope has been fulfilled, this suggests the person has gone from hoping to expecting that what is desired will obtain. This may mean that the person is ignoring “real” facts about the situation. For example, this strong interpretation will not work for at least two of the case studies under consideration in this dissertation: Even though Bonnie hopes to walk again, she certainly can’t act like she can walk when she can’t even move her legs; Kay may hope that she can control her moods without taking her medication, but cannot act like this is so when she becomes manic or depressed again. Although, by the end of his second chapter, Muyskens does seem to support a weaker interpretation of hope and action (described below), he does not actually reject or challenge this stronger claim of acting “as if it were the case” by a person with hope.

The second interpretation, the weaker one, only claims that a person with hope will take a certain approach to her life; that is, she will keep her future open with respect to what is hoped for – the description used in Muyskens’ definition I quoted earlier in this section. Muyskens believes a person keeps the future open via the “non-acceptance of the present tragic situation as final.”¹³ (Muyskens 1979, 26) In other words, a person who hopes for p will typically not act in a way that will make it less likely that what is hoped

¹³ Although this claim is based on the assumption that a person believes the present is awful, and ignores situations, for example, with chronic illness where the person may hope that her present condition remains the same for a long time into the future, the link Muyskens draws attention to between what is hoped for and one’s action still holds.

for, p, can come about. For example, a person who hopes to walk again would not stay in bed all day and refuse to do physiotherapy exercises, as doing these things would work against the future possibility of that person being able to walk again. It is also the case that others may question the sincerity of this person's hope to walk again if she does not demonstrate any willingness to help bring this future event about. One way of "measuring" a person's hope is by considering whether she changes or directs her actions towards achieving this goal and/or takes advantage of opportunities that present themselves that may help her achieve this hope.

This latter comment about others using a person's actions as a way to judge whether that person actually hopes for something is instructive. It indicates that the weaker interpretation is much closer to our common understanding of hope - that a person with hope will act in certain ways is something we expect. There often is and should be some evidence that a person with hope is acting on that hope or, minimally, is not working to foreclose this option.¹⁴ This condition does not make the (different) stronger claim that there will be specific actions, always or very often, correlated with specific hopes. The actions undertaken by persons who hope for a cure for their cancer, for example, can be widely divergent and this is consistent with Muyskens' description of keeping one's life open to what is hoped for.¹⁵

¹⁴ This claim does not mean that a person cannot prudently prepare for the hope not being realized; only that there is an expectation that she will take positive action(s) with respect to what is hoped for as well.

¹⁵ One reason in favour of a definition of hope that addresses the link between hope and action is that in some cases of false hope what is more at issue is the action taken on behalf of a hope (perhaps taking alternative medications) rather than the hope itself (the

From this analysis of Muyskens' definition of hope, an alternative framing for the types of desires that are typically involved with hopes in health care (for example, thinking about well-being as a means of assessing one's desires) has been identified. Although I will not employ the well-being framing in my definition of patient hope, considering well-being does help to draw attention to the connection between what is hoped for and what is of value to that person or what that person's goals are; this is a connection I will expand on below. The association of hope with action or a certain perspective on one's life and possible opportunities for action has also been explored. The relation of hope to action (or avoidance of certain actions) is very important and will be discussed in more depth later in this chapter.

3.4.1: A "Missed" Aspect of Hope

Although the above analysis of different accounts of hope has been useful for developing a better sense of what many of the fundamental aspects of hope are, there are still some important aspects of hope that have not yet been discussed. One such aspect is the role of imagination in hope. Thus, my intention in this section is to: first, present and gain a better sense of this often overlooked aspect of hope; and, second, to demonstrate why imagination is particularly useful for improving our understanding of the role of hope in health care.

In his book, *Images of Hope: Imagination as Healer of the Hopeless*, William Lynch emphasizes the need for a person to have the ability to imagine different

hope for cure).

possibilities for her future in order to be able to hope. Through his experiences as a psychiatrist with persons who are depressed, Lynch notes the important role that imagination plays in being able to see a way out of or a way to deal with one's present situation; persons who are depressed, he claims, are unable to imagine. These persons can't see that their view of the world and the course of their life could be different.¹⁶

Hope must be tied, [Lynch] says, to the life of the imagination, for the nature of hope is to imagine what has not yet come to pass but what is still possible. (Foreward by Leslie H. Farber in Lynch 1965, 9)

While imagination is often associated with fantasy and grandiose wishes, Lynch, and others, want to create room in the definition of hope for imagination to play a creative and positive role. Being able to see the available options for one's future as well as being able to imagine that there are or might be ways of achieving or reaching what is hoped for implies that imagination is part of a process of problem-solving. Lynch stresses that imagination can give one "a wider perspective for life and thought" (Lynch 1965, 23); the type of imagination that operates in hope is linked closely to the "facts" or what is presently true, but it is not limited to a narrow range of options. Yet, Lynch is careful to point out that not everything that can be imagined, and desired, can be hoped for - the same limits, for example, of not being able to hope for things that are impossible, still apply. This understanding of the limits of what can be hoped for and consequently to the role imagination can play in hope is often captured by talking about *realistic imagination*

¹⁶ Of course, this is not all that may be wrong with a person who is clinically depressed. Lynch is focusing primarily on describing this aspect of depression, as he understands it, but does not want to imply that being able to imagine is all that is required to alleviate depression.

or imagination that is tied to the real. As Joseph J. Godfrey (1987) says,

It helps to keep the definition of imagination open. It can be construction or fabrication, presumably illusory; but it can also be anticipatory and receptive. (27)

Godfrey, too, wants to make a place for imagination, as useful and productive, in hope.

Both Godfrey and Lynch argue that hope is not just desire alone, but that the desire in hope is critically connected with imagination. Although desires stem from who we are, what we value, and what we want for our future, when certain doors are closed or things change in a way we didn't expect, these desires sometimes need to be re-evaluated and re-focused or alternative routes for meeting these desires need to be identified. Imagination can help us to do this, as it casts its net broadly for "all" possibilities that could be realizable for us.

Lynch also wants to suggest that not being able to think creatively about one's life and to consider "what could be" makes it more likely that we will not be able to hope and, perhaps, will thereby fall into despair or hopelessness more easily when things don't go our way. Imagination helps us to tell a story about what has happened and to integrate it into our lives, thereby increasing our chances that we will be able to find something to hope for.

To the degree that our images of things and of life are left in fragments we cannot cope. The consequence of not being able to cope is hopelessness. (Lynch 1965, 245)

The task of imagination is to create perspectives for the facts it has found. It will refuse to leave facts as scattered absolutes, to preoccupy and frighten human beings. (Lynch 1965, 243)

These quotes suggest that people have to make sense of the information that they have at a particular time and need to be able to work together in some way the “facts” of their situation with what is of importance to them. The description of imagination’s role in assisting this interpretation of what has happened and could happen in the future, as per one’s ability to hope, fits with an understanding of emotions as interpretive frameworks; i.e., emotions can be understood as a means of determining the salience of information and directing our attention in certain ways. Thus, hope, with the help of one’s imagination and desires, can construct a certain framework for considering, for example, the prognosis and treatment information for one’s disease. (These latter points about emotions as interpretive frameworks will be discussed in more depth in the following section.)

It is worth noting here that interest in imagery and visualization as (potentially) assisting in the healing process has grown over the last twenty years or so. In her book, *Imagery for Getting Well*, Deirdre Davis Bringham surveys the literature in the field of psychoneuroimmunology, which is “the study of the connection between the mind/emotions, the central nervous system, the autonomic nervous system, and the immune system.” (Bringham 1994, 16) She argues that there is increasing evidence that how one imagines oneself in various situations, fighting a disease, etc. can have both psychological and physiological effects. For example, there is evidence to suggest that cancer patients who imagine their immune system, especially the white blood cells, fighting the weak or unorganized cancer cells may contribute to the patient’s survival (see, for

example, Simonton 1978; Spiegel 1989, 1991).¹⁷

It is well accepted among experts that we all image constantly. (The most common imagery consists of negative, non-trusting, insecure, failure-oriented, worried ideation and usually produces behavior and lifestyles of the same nature.) Thus, our mission [she and her colleagues in developing applications of behavioral medicine] is not to teach imagery, but to change and transform existing images into ones that will form the basis for the life and health we wish...Certainly, imagery, is not a substitute for action, but it is a requirement as a model for what is to occur. (Bringham 1994, 33)

This area of research and medical practice helps to reinforce Lynch's claim that the role of imagination in hope should not be overlooked.

A final twist on imagination and hope that Lynch puts forward is that he believes hope involves *imagining with*; that is, a critical part of being able to imagine, and thereby being (more likely) able to hope, is sharing ideas with others, receiving support from others, and even learning about new and different possibilities from them. Lynch wants to challenge the notion of imagination, and thereby hope, as a solitary, individual, private act. Although imagination can have a private side to it, it also draws from persons one is close to, has clinical encounters with, and even from what is promoted in one's culture.

...a more public act of the imagination comes far closer, I [Lynch] think, to describing the saving process that goes on in the modern psychotherapies; two imaginations, that of the patient and that of the doctor, work together to discover and enlarge the possibilities of the situation. (Lynch 1965, 23-24)

¹⁷ There is also evidence that visualization and imagery can assist athletes in improving their performance; indeed, this is one of the bases for sport psychology (see, for example, Ungerleider and Golding 1991).

Lynch discusses the role of public imagination with respect to psychotherapy, yet this process of *imagining together* other possibilities can surely take place in other clinical contexts. It is true that health care providers have a great deal of knowledge and experience with illness and injuries and possible solutions. If and when this information is shared in a caring manner with patients who are struggling to come to terms with their illness or injury and are finding it difficult to hope, new possibilities for hoping can emerge.¹⁸ An example of how further education of medical professionals will likely be able to influence their conversations with patients and the imagining of different possibilities is found in the book, *An Unquiet Mind*, by Kay Redfield Jamison (this is the same Kay with manic-depressive illness I quoted from earlier).

I tried to encourage our clinic doctors to see that this [manic-depression] was an illness that could confer advantage as well as disadvantage, and that for many individuals these intoxicating experiences [manic phases] were highly addictive in nature and difficult to give up. In order to give the residents and interns some notion of the experiences that patients went through when manic and depressed, we encouraged them to read firsthand accounts from patients and writers who had suffered from mood disorders. I also started giving Christmas lectures to the house staff and clinic staff that focused on music written by composers who experienced severe depression or manic-depressive illness. (Jamison 1996, 28)

In this example, I not only see an effort to acquaint the medical staff with what it is like to have this illness, but also an attempt to demonstrate that there are some benefits to this illness and that there are alternate ways of understanding the “noncompliance” of persons

¹⁸ In Chapter Four, I will address the problem of the power health care providers have over patients and the difficulties that are present in ensuring that this power does not translate into the health care provider telling the patient what to hope for.

who are manic-depressive (many people who take medication for this illness have a difficult time staying on the medication when they feel better). All of this information could certainly assist a health care provider in imagining with a person, for example, who has been newly diagnosed with manic-depressive illness and believes that having a mental illness means all hope is lost for a “normal” or productive life.

However, just as a person can imagine that one’s future will be what one wants it to be, one can also imagine the worst.¹⁹ Both Lynch and Godfrey fail to address the fact that imagination can be a “double-edged sword” for hope. It may be the case that for some persons, imagining the worst possible outcome assists them in being able to hope, if they believe that they can cope with that situation. It is also possible that imagining the worst will lead a person to despair, if she believes she cannot cope or would never want to “live like that.” Part of the difficulty with imagining (the worst) is that we may imagine badly. Society’s general unwillingness to accept disability and illness has created a paucity of understanding about and appreciation of the opportunities and challenges faced by persons with disabilities, both physical and mental, and with chronic and mental illnesses – many persons who are considered healthy by society’s standards are greatly frightened by a (drastic) change in their health or level of functioning as a result of an accident or being diagnosed with a chronic or mental illness. In her article, “Toward a Feminist Theory of Disability,” Susan Wendell states that,

[b]ecause of the heroic approach to medicine, and because disabled people’s experience is not integrated into the culture, most people know little or nothing about how to

¹⁹ This is suggested in the quote from Bringham cited earlier in this section.

live with long-term or life-threatening illness, how to communicate with doctors and nurses and medical bureaucrats about these matters, how to live with limitation, uncertainty, pain, nausea, and other symptoms when doctors cannot make them go away. (Wendell 1993, 235)

It is not surprising that people may imagine badly what their life may be like, and thereby find it difficult to hope, in a societal context such as this. The need for accurate information and opportunities to speak with others with one's condition or illness, for example, can become a critical part of reshaping what one imagines in one's future and whether one will be able to hope.

A second challenge to this suggestion that patients and health care providers could and can imagine with each other is the danger of falling into the narrow focus typically taken in health care as to what "good" possibilities are for the future. As I discussed in Chapter Two, there is a strong focus in health care and in society in general on cure; a medicalized view of the future may thereby restrict what possibilities are regarded as "real" options or "successful outcomes" worth hoping for by the health care provider and by the patient. This view of the future may unduly influence the patient's ability to imagine and to hope, especially for something else that is of value to her. Arthur Frank states a similar concern in terms of patients being able to tell their illness narrative (of which I believe hope is or can be a part):

Each [illness] narrative reflects strong cultural and personal preferences. The strength of these preferences presents a further barrier to listening to the ill: both institutions and individual listeners steer ill people toward certain narratives, and other narratives are simply not heard. (Frank 1995, 77)

One of the conditions for hope in health care that needs to be created is the opening up of

the discussion about what are realizable possibilities for patients' futures, broadly speaking, as well as a change in how "success" is defined in health care.²⁰

The upshot of this discussion is that the role of imagination in and for hope, especially as this can be influenced by others, should not be overlooked in discussions of hope. While realistic imagination may be critical for hopes that people have both in and out of the health care context, it seems especially important to place an emphasis in health care on imagination's role in hope as it can have both positive and negative effects on a patient's ability to hope. Given the types of situations that are often encountered in health care, and that for many people their health is an important good, it would seem that being able to imagine with patients a variety of (potentially achievable, sustainable, or acceptable) "futures" for themselves would be one way of enabling patients to discover hope, particularly if cure is not imminent or restoration to their former level of health or functioning is not possible.

I have argued that the "missed" aspect of imagination is essential to a fuller and more comprehensive understanding of hope and its role in health care. The ability for both patients and health care providers to imagine different possibilities for the future is substantially affected by the values the patient and health care provider hold, what the illness or injury is, and the constraints on imagination that are implicitly and explicitly imposed by the medical system. A new definition of hope, one that takes imagination into account, needs to be developed; this is the task I turn to next.

²⁰ I take up this challenge more in the discussion of false hope in Chapter Five and in the discussion of the conditions for hope in Chapter Six.

3.5: The New Definition and Conceptualization of Hope

I have one primary task in this section: to provide a new definition of hope that reflects the previous discussion and fits within the described boundaries. The definition of hope I develop does rely primarily on Muyskens' and Aquinas's accounts, yet, some important changes have been made – namely, I define hope as an emotional attitude, include imagination, and have shifted the emphasis on action. The reasons for these changes will be discussed. The main problem I see with all of the definitions of hope I have surveyed thus far in this chapter and in the hope literature are the two assumptions that: a) hope is a private emotion; and, b) all that needs to be attended to are the interactions between health care providers and patients in order to “take care of” patient hope. These assumptions ignore important contextual features of hope as well as how these interactions and the structure and operation of health care can have a great impact on hope (as I have alluded to in my discussion of imagination). A new definition of hope, one specifically designed with health care, and especially patients, in mind, will aid in addressing these issues.²¹

Martha Nussbaum (1995) claims that emotions are “acknowledgements of the importance of things outside the self that the person does not control...” (390) She argues that emotions are expressions of human dependency and that this fits with a view of the self as social, relational, and interdependent. Our reliance on others and our inability to control all aspects of our relationships and environments entails that things may not go the

²¹ Chapter Four will provide the normative framework for examining current practices in health care with respect to hope.

way we want them to; emotions allow us to evaluate and respond to these changeable situations. Some of our emotions, especially those of love, trust, and hope, help us to create relationships and connections with other persons. While these relationships can make us vulnerable to the harm and hurt these others may cause, these relationships also allow great joy and strength and can provide a means of support and comfort in difficult times. Ultimately, the underlying claim made by Nussbaum is that many of our emotions go beyond the mere “feel” or “feeling” of that emotion (the physiological manifestations); emotions are a way in which we interact with our world and many or most of our emotions are a complex mix of beliefs, judgements, and feelings.

One way of capturing this claim that an emotion is more than just its “feeling” is to label it an emotional attitude. The “attitude” part of this label helps to foster attention to the complexity and endurance of some emotions. An emotional attitude suggests a certain way of understanding, evaluating, and reacting to one’s world and the changes one experiences in it. “[I]nsofar as emotions are felt of, toward, or about things, they are not just brute “feels”; they are a way of being conscious or aware of the world.” (Calhoun and Solomon 1984, 16) Given the magnitude of information that one is confronted with in daily life, the ability to screen out some of this information and to attend to what is considered to be relevant at any one time is assisted by one’s emotions. As Ronald de Sousa explains,

For a variable but always limited time, an emotion limits the range of information that the organism will take into account, the inferences actually drawn from a potential infinity, and the set of live options among which it will choose. (Sousa 1987, 195)

In other words, emotions or emotional attitudes are salience-determining as well as action-directing. If we consider the previous discussion of hope, it has already been demonstrated that hope, or what is hoped for, gives shape to how one makes sense of and interprets a change in one's health status and related test results, treatment options, and strategies. As an emotional attitude, hope helps an individual to draw together this information (or certain portions of it) with what she values or wants.

Based on the preceding discussion, I offer a new definition of hope:

Hope is an emotional attitude whereby the person who hopes for p (where p is the event or state of affairs hoped for): a) desires/wants p ; b) believes p is in accordance with her values and/or goals; c) imagines p is a realizable possibility for her, even though it is uncertain whether p or not- p will occur; and, d) acts in such a way as to support her hope (i.e., where it is possible to affect whether p will occur, she will try to bring p about; minimally, she will not act to foreclose the possibility that p will occur) - this may include making use of available opportunities and resources (personal, material) and/or relying on other individuals.

While condition a) has been discussed previously in this chapter (see Section 3.4 in particular), conditions b), c), and d) make important additions and/or changes to the “standard” or “typical” definitions of hope.

Condition b) provides a limit for the desires that can properly form the basis of patients' hopes - a patient will hope for a state of affairs or event that is in agreement with her values and/or goals. This condition is weaker than what Muyskens proposed: recall

that Muyskens' condition required p to be constructively connected to the person's concept of herself or her well-being. Condition b) is weaker in the sense that focusing on the values and goals of the individual provides a broader basis upon which hopes are understood to reflect what is important to that person and can be "valid" hopes. Although a person may further believe that her hope contributes to or conveys what she believes is in her well-being, the new condition does not make this judgement a necessary requirement of having hope. As well, drawing attention to the role that values and goals can play in shaping what is hoped for sets the stage for discussion of the different goals and value frameworks that may exist between, and among, patients and health care providers.

Condition c) claims that the person with hope imagines p is a realizable possibility for her, even though it is uncertain whether p or not- p will occur. This condition draws together a number of points about uncertainty, possibility/probability, and imagination that were discussed earlier in this chapter. Given that the importance to the person of what is hoped for may allow her to hope in a situation where it is highly unlikely (although still possible) that what is hoped for will occur, this condition does not make this type of hope an "exception to the rule." In fact, the only restriction this condition places on what can be hoped for is that p be a realizable possibility for that person. This wording captures the sense that one's imagining of future possibilities does need to be tied to some facts about the current situation, but that these facts can be interpreted in differing ways by, and among, patients and health care providers. Perhaps the most common example of these varying interpretations is with cancer survival statistics. Some patients, upon hearing the

“5% survival after five years” prognosis, may react by concluding that there is still a chance to survive whereas others may believe that the odds are against them and that survival is not a realizable possibility (and that they should adjust their hopes accordingly). In other words, what is considered to be a realizable possibility for an individual is subject to disagreement.²²

Condition d) makes explicit the connection between hope and action, namely that a person with hope will act in a manner that supports (or minimally does not foreclose) the hope. This condition takes account of the expectation that an individual with hope will “do” something on the basis of that hope; in other words, there are behavioural implications to having hope. We will see shortly that the “action” aspect of hope is a feature that distinguishes it from, for example, wishing and being optimistic. This condition also acknowledges the use of resources (internal/external), opportunities, and reliance on other individuals that may figure in how a person with hope acts or works towards the realization of her hope. Morrie offers a nice example of how his ability to hope, even though he is dying, relies on and is affected by his close relationship with his wife:

Say I was divorced, or living alone, or had no children. This disease-what I’m going through-would be so much harder. I’m not sure I could do it. Sure, people would come visit, friends, associates, but it’s not the same as having someone who will not leave. It’s not the same as having someone whom you know has an eye on you, is watching you the whole time. (Albom 1997, 92)

²² I will argue in Chapter Five that this potential disagreement is one of the factors in cases of false hope and will further explore in that context the meaning of “realizable possibility.”

Recall that Aquinas suggested experience, riches, instruction, other individuals etc. can all affect whether a person has hope, since their presence or absence can affect the assessment of whether a hope is achievable. By drawing attention to the resources and other individuals that are available to a person with hope, or who is trying to hope, this allows room for questions about and considerations of an individual's context and social situation to enter into assessing what the responsibilities of others, such as health care providers, may be. It also allows one to undertake a critique of broader social norms, such as the discrimination against persons with mental and physical disabilities, that may impact on what a person is able to hope for. It may be extremely difficult, for example, for a person to hope for a happy life if she has recently become disabled, given the stereotypes that exist in our society about disability. Finally, this condition helps to set the stage for determining the responsibilities of health care providers with respect to patient hope via the actions that a person with hope may take (and those that a person without hope may take). In other words, if health care providers foster certain hopes for patients, such as the hope for cure, then they may have a responsibility with respect to the actions the patient with that hope takes (and not just a responsibility for fostering the "feeling" of hope). This point will be addressed more closely in Chapter Six as the role of health care providers with respect to patient hope is reviewed.

A few further comments about the types and range of actions that will "count" as meeting this condition for hope are necessary. First, I want to allow a broad range of actions to count: these actions can stem from the more obvious, such as taking one's pills and keeping up-to-date on research trials for one's condition, to monitoring and adjusting

one's exertion level if one has a chronic illness, to the less obvious actions of prayer or even a perfectly ordinary task such as cleaning out the closet one meant to get to. Second, since hopes can fluctuate and change, part of acting on one's hope may involve re-evaluating a particular hope, re-evaluating one's adjustment to an illness or injury, or even deciding that what one hopes for has been accomplished to some degree. Accordingly, working on or towards one's hope does not have to involve physical action, but can include self-reflection, spiritual, and emotional components as well.²³ Third, part of determining whether a person hopes may also include the actions the person does *not* take. For example, a person who hopes to recover from her surgery in time for a favoured concert series would not be expected to give away these tickets or cancel a long-standing reservation at a favourite pre-concert restaurant. Ultimately, being open to thinking about a variety of ways in which hopes can be supported and worked towards should assist in developing a better sense of the conditions in health care that need to be fostered for patient hope - but I leave this (primarily) to Chapter Six.

3.5.1: Hope, Optimism, and Wishing

To round out the analysis of hope contained in this chapter, it seems prudent to explore two concepts often believed to be similar to hope, namely optimism and wishing. Our common understanding of these three concepts is that they are closely interrelated,

²³ Allowing this broad range of activities that can count for acting on hope is supported by Dufault and Martocchio. In their article, they claim that actions may “fall into one or more of four realms: psychologic, physical, social, and religious” (Dufault and Martocchio 1985, 385). They provide a variety of examples of actions for each of these realms - much as I have done, and will do, in the following chapters.

yet cover somewhat different terrains. By gaining a better sense of the ways in which hope is similar and dissimilar to optimism and wishing, it will become more apparent why hope is of greater importance in health care than optimism and wishing.

In a study where patients were asked to describe the difference between wishing and hope, Dufault and Martocchio (1985) found that:

People described the difference between a hope and a wish with ease. A wish differs from hope in that it [the wish] is not perceived as within the realm of possibility in the present or future. (385)

In other words, to wish is to have a desire for some thing or state of affairs that one acknowledges is (most likely) unattainable or beyond one's reach. Hope and optimism are distinguished in that optimism seems not to involve specific desires, but refers more to an outlook on or approach to life. Snyder (1991) defines optimism "as the generalized expectancy that good things will happen" (288); Webster's dictionary (1989) concurs with this definition as it describes optimism as "an inclination to put the most favourable construction upon actions and events or to anticipate the best possible outcome."

However, this distinction between hope and optimism is less than precise, for we can, and do, say both: (1) that a person is optimistic about specific events; and, (2) that a person is, generally speaking, hopeful about her future. Yet, a common feature of hope and optimism has been identified, namely that each of these concepts involves a desire for some thing or state of affairs judged to be "good" by the individual.

In Farran, Herth, and Popovich's book (1995), *Hope and Hopelessness: Critical Clinical Constructs*, the authors also compare wishing, hope, and optimism. The following

example of each concept is taken from a chart in their book: (see Farran, Herth, and Popovich 1995, 12)

Wishing	Optimism	Hope
The biopsy came back positive for breast cancer. I think the lab made a mistake.	The biopsy came back positive for breast cancer. I know that everything will be fine.	The biopsy came back positive for breast cancer. I am very frightened. I face a radical mastectomy and possible chemotherapy. I do not know my prognosis, but somehow I will manage.

Interestingly, these examples don't give a simple statement of what the wish or hope is; instead, a context (of having a positive biopsy for breast cancer) is given within which an imagined response suitable for each concept is described. It may not be immediately obvious how the example for hope actually demonstrates hope, in that the person is expressing the belief that she will (somehow) manage. Herein lies the hope - the fear and uncertainty about the future is acknowledged and yet the person anticipates that she will manage and make it through this difficult time. But, when people wish or display optimism, they tend to focus primarily on the positive aspects of the situation and ignore the whole range of possible outcomes to what has happened or could happen. In other words, when one is wishing or is being optimistic, one is much less likely to contemplate the "bad" things that could happen or to deal with one's negative feelings. Hope, in contrast, tends to be more open to one's feelings, both positive and negative, and acknowledges the possibility that one could be hurt, disappointed, and/or frustrated in the future if the hope is not realized. Hope is therefore more likely, as compared to wishing

and optimism, to reflect a balanced assessment of the situation. (Recall Hume's suggestion that hope is a mixture of sorrow and joy.) This helps to explain the general sense that, out of the three constructs, hope is probably the one most in touch (or has the greater chance of being in touch) with reality.²⁴

A second difference between hope, wishing, and optimism is also suggested by the given examples - their connection to action. According to my definition of hope, if a person hopes for a certain state of affairs, she will act in ways that will help attain or support that hope. By comparison, wishing and optimism are less likely to involve action. In his book, *The Psychology of Hope: You can get there from here*, C.R. Snyder claims that optimism does not lead to "goal-appropriate" actions. He states that,

...optimism leads us on to expecting the best, but it does not necessarily provide any critical thinking about how we are going to arrive at this improved future...optimists believe positive things will happen to them. Optimists do not necessarily have clear plans for getting where they want to go [unlike people with hope]. (Snyder 1994, 13-14)

In other words, optimism will not directly alter a person's actions towards achieving some goal, instead, the person will "keep on doing what I'm doing; things will work out, they have before." Farran, Herth, and Popovich (1995) state that: "...persons who wish often engage in few behaviours that work toward obtaining the "wished-for" positive outcome." (11) Why? They argue, and I concur, that wishes have a very low likelihood (if that) of coming true; accordingly, wishes are rarely followed up with action. Also, since wishes may be less connected to reality, it may be more difficult for the wisher to discern a

²⁴ False hopes - as not being reality-based - will be discussed in Chapter Five.

plausible course of action for realizing the wish, as compared to what is hoped for.

Overall then, we have seen that hoping, wishing, and optimism are not mutually exclusive concepts, even though some differences between these concepts do exist. The main similarity between these three concepts is that each involves a desire (or desires) and associates these desires with a better/favourable/manageable future. However, wishing and being optimistic about the future will often not lead to actions that will help to realize what is desired, while hope is directly connected to action. In addition, there is a sense that hope is more (or has the greater chance of being) reality-based. Given these differences between hope, wishing, and optimism, hope is of greater importance in health care because: (1) patients will act on their hope - leading to the need for attention to the actions taken; and, (2) what is hoped for by patients will often reflect their assessment and understanding of their illness or injury and how it fits (or doesn't) with their life, and this can help to open up conversation about different strategies and options for coping in a way that wishing and optimism might not be able to encourage.

3.5.2: Hope's Opposites - Despair, Fear, and Hopelessness

It is important to consider the opposites of hope, as these are emotions that will also be expressed and experienced by patients in hospitals. When a person's health status changes, there can be new and sometimes difficult information to process. If there is something a patient hopes for (p), there is also likely something that person may fear (not-p) or the person could despair that p will not come about. Questions about how a health care provider can encourage hope and yet still be honest about the patient's condition,

especially when the prognosis is poor, help to capture the sense that patients could go “either way” with their emotional response. Thus, exploring the opposites of hope can lend some insight into what conditions may affect or influence whether a patient has hope, fear, or despair.

Perhaps the most obvious opposite of hope is hopelessness (often interchanged with despair).

What, then, is hopelessness?...it is one or a combination of a number of powerful human feelings...One of these feelings, most habitual of all in hopelessness, is the sense of the impossible: what a man must do he cannot; no matter what he does it leads to a sense of checkmate; he is in a trap...A second powerful feeling is that of too-muchedness: life is too much for us...A third powerful feeling...is that of futility: what is the use? (Lynch 1965, 48)

As Lynch conveys, when a person feels hopeless, she believes that what she desires will not come to pass (there are no routes to achieve it, everything attempted has failed) and that there is no reason to continue hoping. Yet, as the following comment by William Ruddick demonstrates, a few further refinements to the definition of hopelessness (and hope) are required.

...we should not assume that the loss of hope is always harmful. Not all hopelessness is despair, with resulting refusals of treatment and suicidal desires.... We need a distinction between being without hope and the emotionally fraught condition of being bereft of hope. Which of these two states of hopelessness patients incur may turn on the content and strength of their prior hopes and the manner in which they lost those hopes. (Ruddick 1999, 346)

First, as indicated by Ruddick, there is a need to distinguish between different types of hopelessness. Hopelessness, in terms of being without hope, implies that the

person accepts that something is beyond her reach or control and decides to put her energies elsewhere. She is still able to hope for other events or states of affairs. In contrast, hopelessness, in terms of being bereft of hope, captures the description given above by Lynch and conveys the despair and sense of loss experienced by the individual.²⁵ The underlying clarification required here is that being without hope usually applies to a particular aspect of a person's life or to something that a person desires, but it is not a comment in general about the person's outlook on life. Describing a person as hopeless or experiencing hopelessness often refers to her general demeanour and implies that the person has given up or is undergoing a crisis of confidence. As it is typically used in conversation, hopelessness conveys both the sense that what was hoped for is not attainable on that person's view, and that this assessment has spilled over into other parts of the person's life making it difficult or impossible for her to hope for anything else (except perhaps an end to her suffering).

Second, it is also important to acknowledge that hopes can fluctuate and change over time. Accordingly, a person may be without hope one day and find it the next or vice versa. The role of health care providers in being able to respond to these fluctuations as well as being able to identify and assist those patients who can no longer hope or are generally hopeless is a critical part of learning what conditions in health care can affect patient hope. The danger is that if hope and hopelessness are seen as discrete categories, rather than as on a continuum over various parts of a person's life or as (sometimes)

²⁵ Ruddick's observation that the manner in which a hope is lost (as well as what it is for and its strength) will be discussed in Chapter Four in the section on vulnerability.

fluctuating, the individual nature of a patient's hopes may be overlooked. The historical accounts cited earlier in this chapter described despair as a desire for something without the belief that this could be obtained. This definition helps to capture the sense that the same situation and the same information can be interpreted by people in different ways which could lead either to hope or a lack of hope. It is also the case that,

[t]he same context can provide opportunities for both hope and hopelessness; for hope regarding one outcome and for hopelessness regarding another outcome. (Dufault and Martocchio 1985, 389)

Fear is also considered to be an opposite of hope; however, fear is an opposite in the sense that what a person wants not to happen is judged likely to come about. In other words, if a person hopes that *p*, then the fear is that *not-p* will be realized. It may be the case that what is hoped for has a small possibility of being attained (such as a cure for her cancer) and the available evidence (from lack of response to chemotherapy, increased pain) is that the cancer will not be cured leading to the fear of this outcome because the person does not want to die or does not want to experience a painful death.

Little is said in the hope literature about why a person may shift from hope to fear or vice versa. Wayne A. Davis suggests that it may be a matter of "mood" as to our use of the terms hope and fear:

Indeed, it seems that whether we use "*S hopes that p iff S is afraid that not-p*" rather than "*S is afraid that not-p*" depends on things like our mood. In a positive mood, we say we are hopeful of successes, and hate to concede any fear of failure. In a negative mood, we say we are fearful of failure, and only grudgingly admit any hope for success. (Davis, 1987, 292)

But, I suspect that whether a person expresses hope or fear relates to more than just mood. A change in a person's illness/injury, new information, a loss/gain of resources and support, and interactions with health care providers (and family and friends) can all affect a person's sense of whether p or not-p will come about. Also, if we recall Hume's exception for fear, that the magnitude of what is feared may cause this emotion even though its likelihood is very small, it could be the case that a person's fear could overwhelm her ability to hope. In other words, the importance of what is hoped for (or feared) could be a determining factor in someone's emotional response. It may also be the case that a person can hope in the context of fear or vice versa, i.e., hold both of these emotions concurrently, given that each involves a different state of affairs.

As such, it appears that hope and fear are emotions that can, and almost always will, be held in tension with each other.²⁶ Recall Hume's explanation of these two passions: that they are the result of a mix of joy and sorrow. As one's assessment of the likelihood of joy or sorrow shifts when, for example, new information is gained, the individual will experience either hope or fear. This tension or linking between hope and fear is in contrast with a person who has lost hope and is in despair. It is precisely because this person is unable to hope - she believes that what she most desires is unachievable or has had her hope destroyed in an uncaring manner - that she is experiencing despair. One cannot hold both hope and despair in tension with each other. Noting this difference between these two opposites of hope may be relevant for health care providers when

²⁶ Given the difficult situations patients are often faced with when their health changes, this "tension" between hopes and fears may be especially present in or felt by patients.

trying to initiate discussions with patients about hope.

Ultimately, both despair and fear are opposites of hope and can give important clues as to the ability of patients to hope and what they may hope for. If health care providers are to foster conditions for hope, being aware of these other emotions and how they relate to hope can provide feedback as to how well these conditions are operating.

3.6: Conclusion

Many definitions of hope exist and the goal of this chapter was to develop a definition of hope that would work within the boundaries I specified at the outset of this project. Via an examination of historical and phenomenological accounts of hope, a better sense of the important features of hope common to many, if not all, definitions of hope was derived. These features were further rounded out by consideration of the role of imagination in hope. Throughout, the patient's perspective on hope and illness/injury was utilized to test and clarify what hope is in health care. As a result, the new definition of hope stresses the subjective nature of hope as well as the link between hope and action. Finally, comparisons of hope to wishing and optimism and its opposites of hopelessness/despair and fear were made. Chapter Four will provide the ethical framework, within which this definition of hope will be a key factor, for exploring the nature of false hope (Chapter Five) and the conditions for hope that need to be fostered in health care (Chapter Six).

Chapter Four

Grounding the Analysis - Caring about Hope

“It is only with the heart one can see rightly,” the fox says to the Little Prince. “What is essential is invisible to the eye.”
Antoine de Saint-Exupéry, The Little Prince

4.1: Introduction

In the previous chapter, part of the discovery of what hope is relied on comparisons between hope and other emotions such as joy, despair, and fear. By situating hope among similar and contrasting emotions, we learned that hope is closely connected to these other emotions and often exists in tension with them. In this chapter, I want to pull more on this recognition - namely, that a person with hope (under the conditions specified) can, to some extent, be seen as “poised” between hope and fear or despair as well as between hope and joy. That is, part of what makes hope hope is the awareness that not every hope is realized or that hope comes with the possibility of disappointment. Acknowledging this feature of hope, that it is based in uncertainty, helps to draw out the point that people with hope make an emotional investment in their future and take a certain stance towards its uncertainty. The implication of this is that having hope can make one vulnerable; to hope opens one to the possibility of being hurt by circumstances not working out or, importantly, by others who may not support, may ignore, or may dash (intentionally or not) one’s hope. Thus, the first section of this chapter will be spent exploring the various forms of vulnerability connected with hope as well as the significance of vulnerability for understanding the role of health care providers with

respect to patient hope.

By the end of the section on vulnerability, two related points will be raised that will require further development: (1) relationships are central to hope - I have already suggested this in Chapter One and will continue to build on this claim; and, (2) given the importance of relationships for hope, the ability of traditional approaches to ethics and bioethics to provide adequate guidance on how to ethically address patients' hope needs must be questioned. If, as I contend, relationships are a key aspect of hope, then there is reason to pursue this line of inquiry in more depth. Traditional ethical theories seem less able to inform this inquiry as compared to an ethical framework that not only focuses on relationships, but is adept at analysing and evaluating these relationships and their context. Accordingly, the framework I describe and develop in this chapter is grounded in feminist theory; and, in particular, in a feminist version of ethics of care developed by Joan Tronto. The reasons for choosing a feminist care ethics perspective will be explored more below. But suffice it here to say that it is from this perspective that the responsibilities of health care providers with respect to patients and their hope(s) can be best addressed, as attention is given to the power imbalances in these relationships as well as to the contextual, structural, political, and hierarchical nature of medicine. Crucially, this framework will draw our attention to the practices of care in medicine as they relate to and are about hope, and will provide a means for critiquing and changing these practices (the tasks I undertake in the following two chapters).

4.2: Vulnerability

There has been much discussion in the bioethics literature, especially in feminist bioethics, about the vulnerability of patients. Concerns about health care providers exacerbating or taking advantage of this vulnerability have led to stricter controls on research and more emphasis on informed choice. This general vulnerability of patients forms the backdrop for the following discussion of the vulnerability(ies) associated with hope. Relatively little has been said in the hope literature about vulnerability and hope, yet, the risks that accompany having hope, trying to hope, and sharing one's hopes with others need to be acknowledged. This acknowledgement seems especially important when persons are ill or injured as their dependence on others, particularly health care providers, will be heightened and more fully exposed. As I will demonstrate, there are (at least) three different ways in which a person can be vulnerable with respect to what she hopes for: (1) due to the uncertainty of what is hoped for, she may be hurt and disappointed if the hope is not realized; (2) sharing her hope with others opens her to the possibility that these others may not support that hope; and, (3) having hope means that she will be sensitive to information, both positive and negative, related to what is hoped for. Exploring possible responses by health care providers to these forms of vulnerability will round out this section.

The following excerpt from Bonnie's description of her hospital experiences picks up about two months after her second stroke. What Bonnie relates helps to illustrate the vulnerability associated with a patient's hope(s) and gives some insight into what different types of vulnerability may exist.

The first sounds were breathy, less than whispers. My Jackie Kennedy voice, Terre [a close friend] called it. The therapists called it “not functional.” It was hard work. I learned the economics of speech. To measure my words, as the cliché goes. When it’s so difficult to get ideas across, most of them seem hardly worth it...

The speech therapist said that I would never regain normal speech. I could try, and she could help, but we were doomed to failure. The damage had been done, and we had to be “realistic” in our expectations. She was cool and brisk, as if she had just stopped off at the hospital on the way to doing something really important, like preparing to give a dinner party.

I was devastated. How could I be me if I couldn’t speak? Who the hell did she think she was? Who taught her it was her job to make me “realistic,” to dash my so-called false hopes? *I was talking!* Real words. I had no strength to project them, but they were all there. Or mostly there. I could only get out a few words at a time, so my phrasing was weird and irregular. My thick tongue made my words slurred and people had trouble understanding me. I had to repeat everything as I became more fatigued. Requests came out as baby talk or one-word commands: “Radio,” not “Would you please turn on the radio?” Sometimes I grunted. But it just wasn’t conceivable that this weak voice would not strengthen with time and practice.

I can’t remember the speech therapist coming after that. Maybe she just gave up on this hopeless case. I don’t think she did any speech exercises with me, not even the tongue movements and clicks I had done after my first stroke. And she never had the decency to admit that I was doing better than she had predicted, or to congratulate me. (Klein 1997, 169-170)

In this excerpt, Bonnie’s vulnerability with respect to her hope to talk again is poignantly captured. Bonnie lacks the ability to do things for herself and is very reliant on others for assistance. She needs someone to turn her radio on and off (and relates in her book how she would sometimes not be able to get anyone’s attention and would have to listen to music she detested for long periods) and has to rely heavily on her friends and family to

take the time to really listen to what she is saying. Relatedly, and importantly, we learn that Bonnie does not have the chance to disagree with the speech therapist about her assessment of Bonnie's potential to regain normal speech. The speech therapist fails to appreciate how wrapped up the ability to talk is with Bonnie's goals and her understanding of the possibility to continue her work. By not addressing this, the speech therapist ignores how Bonnie, the person, is affected by the strokes and seems to misjudge how hard Bonnie will work to achieve the ability to speak again. The speech therapist's dismissal of the situation as "doomed to failure" does little to convey a sense of caring about Bonnie's hopes (and fears) with respect to her recovery. As Bonnie herself asks, is it the responsibility of the speech therapist to dash Bonnie's "false" hope? Given her dependence on the speech therapist for support, it is clear that Bonnie resents the way her hope was challenged, and potentially destroyed, by this individual.

Since a patient's hopes will express what is important to that person, in terms of her desire for a particular goal and/or what she values, one way in which this individual can be vulnerable is with respect to what is hoped for. This is perhaps the most obvious vulnerability associated with having hope. As Donald Capps (1995) explains: "Hopes are projections that envision the realizable and thus involve risk." (53) Since hopes are one way of expressing what really matters to oneself, it is risky to "name" one's desires and to hope for these - one may be extremely disappointed or devastated if these hopes are not realized. "When our hopes fail, we take it very personally because in hoping we invest ourselves, putting our very existence on the line." (Capps 1995, 75) Luc Bovens (1999) explains that hope, or hoping, "involves more of a conscious endorsement of the value of

the projected state of the world..." (679). He concurs that having hope may involve some risk for the individual because there is a wanted or desired state of affairs expressed by that hope. Thus, at a very basic level, to hope exposes one or makes one vulnerable to the sense of loss or hurt that may be experienced if this hope does not come to pass; and, the more important the hope is to the individual, the greater that sense of loss or hurt may be.

Identifying one's hopes to oneself may be risky, but naming one's hopes to others is also risky. If hopes are shared with others, there are the attendant risks that these others will scorn, laugh at, or reject what is hoped for or will simply ignore what is said (as in Bonnie's case). David Barnard emphasizes the importance of others responding to and acknowledging one's hopes, even if these others don't ultimately agree with the hope.

At the interpersonal level, part of the inspiring power of hoping is the affirmation and confirmation that comes from having our hopefulness mirrored back to us in the empathic responses of others. The very act of inventing and telling new stories, in other words, implies that someone is there to hear them. An environment that cannot or will not hear our stories is an environment that is inimical to hoping.

(Toombs, Barnard, and Carson 1995, 51)

There may also be the related risk of embarrassment and/or shame if one tells others what one's hopes are and these hopes are not realized. Thus, a second way in which persons with hope are vulnerable is in terms of how others respond to what is hoped for. This vulnerability may be especially acute if one shares one's hopes with someone else who is held in high esteem, or who is depended upon for care, or whose opinion and support are cherished.¹ There is a sense in which sharing one's hopes with these "chosen" others can

¹ Recall Morrie's comments about how it was easier for him to hope and to make the most of his remaining days due to his intimate and supportive relationship with his

help to create intimacy (for an individual will often not share her hopes with everyone), but the price of this intimacy is being “exposed,” and hence vulnerable, to the reactions of these others.

Yet, it is not only the hurt that may result from a hope not being realized or not being supported by others that can make a person vulnerable. Indeed, the emotional energy that one devotes to and invests in that hope and its imagined future will affect one’s sensitivity to information and comments/actions by others that relate to what is hoped for - a third form of vulnerability. This sensitivity can be present whether the hope is shared with others or not. As the definition of hope arrived at in Chapter Three contends, hope is an emotional attitude: when a person has hope, her attention is directed in certain ways and the person preferentially focuses on (or ignores) information/details that are judged to be relevant to that hope. Remember that hope, as an emotional attitude, is salience-determining and action-directing. Information about a particular illness that a person looks up on the internet can easily dash her hopes or, alternatively, a story overheard between people in the elevator at the hospital can hold out the possibility of hope. Given that health care providers occupy an established social position of help and support for persons who are ill or injured, patients may pay particular attention to what these health care providers do and do not say as well as the way they respond to questions or comments relevant to particular hopes.² For example, depending on what is hoped for

wife. One can imagine that Morrie would not be able to face his death with so much hope if his wife did not share this hope with him.

² Obviously, the second and third forms of vulnerability can operate together or overlap, such as when a person looks to another for support for hope and receives

by a patient, an off-hand comment from a health care provider about how another patient fared with the same illness may reinforce or destroy a patient's hope.

Clearly the latter two forms of vulnerability take on a special significance in health care. As already discussed, due to the specialized knowledge that health care providers have and their ability to control access to treatments and other forms of assistance, many patients will rely on health care providers to support their hope(s). As we saw with Bonnie, her relationship with the speech therapist was of significance in terms of her ability to hope to re-learn how to talk. Although Bonnie refused to give up her hope, and found support for her hope in her friends and family, the speech therapist was someone that Bonnie (naturally) turned to for help and believed would help. Both the lack of support she received and the way in which this message was given made it hard for Bonnie to continue with her speech exercises and to hold onto her hope (at least over the short term). Bonnie's situation helps to demonstrate that hope cannot, most often, be sustained by the patient alone or pursued by the patient alone. It may not only be difficult for a patient to discover hope, but also to continue to have hope, especially if what is hoped for differs from the information and messages she receives from her health care providers. The concern then is that health care providers may discount or try to push patients to change their hopes before patients are ready and/or even perhaps before it is clear that the hope will not be realized. Further consideration of the nature of vulnerability will be of assistance in developing this point.

information about what is hoped for from that person. Yet, these two versions of vulnerability can function separately as I have described.

In his book, *Protecting the Vulnerable: A Reanalysis of Our Social*

Responsibilities, Robert E. Goodin gives the following definition of vulnerability:

Vulnerability...is a relational notion: a full specification will tell us who is vulnerable to whom with respect to what. Saying that A is particularly vulnerable to B with respect to X clearly fingers B as the agent who should be particularly responsible for seeing to it that A's interests in X are protected. Vulnerabilities, and the responsibilities growing out of them, are not only relational but also relative. A is more vulnerable to B (1) the more control B has over outcomes that affect A's interests and (2) the more heavily A's interests are at stake in the outcomes that B controls. (Goodin 1985, 118)

Goodin is interested in giving an account that will explain the responsibilities we have in "special" relationships, such as those between parents and children, friends, and professionals and clients; he argues that vulnerabilities and responsibilities arise out of these relationships due to the connections, interactions, and agreements that exist between these individuals.³ As such, this definition of vulnerability fits closely with what has been discussed above re: the power of health care providers to influence what patients hope for. Of note in Goodin's definition is his attention to the fact that a person's responsibility

³ Margaret Urban Walker undertakes an in-depth analysis of Goodin's account of vulnerability and responsibility in her book, *Moral Understandings: A Study in Feminist Ethics* (1998). She further expands on Goodin's account and allows that it does work well for "the special obligations of promisors, parents, employers, professionals and friends..." (Walker 1998, 83). However, she does point out that: "...someone's having a vulnerability depends on his or her important needs' being potentially answered. But who might be responsible to see to that person's need (and in what fashion and to what degree and why), i.e., to whom, if anyone, that person is vulnerable, is determined by quite specific forms of *connection*." (Walker 1998, 85; author's emphasis). As I have been arguing, the patient-health care provider relationship does create an intimate connection between these individuals, such that patients are often vulnerable to what their health care providers say and do.

changes with the degree of power that person has over the consequences that matter to or will affect another person. This framing of vulnerability and changing degrees of responsibility fits well with the current hierarchical structure of medicine. For example, doctors have the most power and are afforded the primary responsibility for patients; as such, it is fair to claim that physicians also have a primary role to play with respect to patient hope. But, to the extent that each health care provider interacts with patients and has the power to influence what is hoped for, each shares a corresponding degree of responsibility for ensuring, at the least, that the vulnerability of each patient is not heightened and her ability to hope, generally speaking, is not destroyed (even though specific hopes can be destroyed). Goodin's definition also helps to draw attention to the individuals and/or organizations that set and influence the context of care. Administrators, insurance companies, hospital boards, and government officials can all make decisions that affect what services are available for patients and that likewise structure the relationships between health care providers and patients. Thus, these (albeit more distant) "others" also share some degree of responsibility for attending to patient hope and vulnerability.⁴

Sorting out the connections between hope and vulnerability in terms of what is hoped for, its likelihood of being realized, and the role of others is obviously complex. But a further layer of complexity is added as we consider what an appropriate acknowledgement and response(s) by health care providers would be to these forms of

⁴ For further discussion of the advantages and disadvantages to taking Goodin's approach to vulnerability and responsibility, see Walker 1998, Chapter Four. Later in this chapter (see Section 4.5) and in Chapter Six, I will consider in more depth the role of those organizations and individuals mentioned above that have input into the context of care and what their responsibilities are with respect to patient hope.

vulnerability connected with hope. Minimally, it seems that health care providers should be aware of these potential vulnerabilities. But how should this awareness influence and direct a health care provider's actions with respect to patient hope?

Goodin describes vulnerability as “essentially being under threat of harm” (Goodin 1985, 110) and states that the vulnerable need to be protected from this threat of harm. This claim is relatively common and agrees, I believe, with most interpretations of how those who are vulnerable should be conceived. However, in stressing the vulnerability of patients with respect to their hopes, I am concerned about thereby making a connection between hope and the need to protect patients. Although there are situations in which patients do need to be protected, such as with proper guidelines for research participation, it is not clear that protection is what is required with respect to patient hope (as well as other emotions).

One reason for my concern is the possible interpretation of protection of the vulnerable with respect to their hopes as justifying paternalistic intervention. Protecting the vulnerable could be interpreted as implying that health care providers should promote certain hopes for patients as a way of protecting them from the truth and thereby making things easier on them.⁵ In other words, stressing the vulnerability of patients with respect to their hope(s) could make it more likely that health care providers will *assume* they know what is best for patients and foster what they, the health care providers, believe to

⁵ The following explanation of paternalism by Susan Sherwin helps to reinforce my point: “Because paternalism aims for the patient’s good, it is recognized as a well-intended action, but its actual achievement in bringing about the best consequences is in doubt, because it is the physician’s - rather than the patient’s - perception of the patient’s good that is decisive.” (Sherwin 1992, 138)

be the appropriate hopes for those patients without adequately identifying and responding to patients' own hope needs. And, as Ronna Jevne points out, a focus on protection must be tempered by the possibility that health care providers (among others) may sometimes try to dissuade patients from hoping for some state of affairs that is a "long shot" out of concern for those patients, but also for their own sake.

...[W]e do not want people we care about to be disappointed [if/when their hopes are not realized]...Indeed each of us must wrestle with the vulnerability of those we care about. As legitimate as this is, we may also need to recognize that we may be protecting ourselves. We don't know what to say or do if the hope is not fulfilled. If we allow ourselves to think there is a window of possibility, when it is closed, we too will hurt. (Jevne 1996, 1)

Joan Tronto addresses practices of protection in a discussion of various forms of care and finds that,

...some activities are both partly activities aimed at care and aimed at another end. Protection represents such an activity. By protection I refer to the warding off of extraordinary incursions of violence or other forms of disruption into our daily lives....though we might say that protection involves assuming a burden for others in the same way that caring does, in fact protection involves a very different conception of the relationship between an individual or group, and others, than does care. Caring seems to involve taking the concerns and needs of the other as the basis for action. Protection presumes the bad intentions [threat from] and harm the other is likely to bring to bear against the self or group, and to require a response to that potential harm. (Tronto 1993, 104-105)

In other words, while protection may (seem to) meet the needs of those being protected, the stance taken toward those individuals is quite different from a caring approach. In protecting someone, the focus is on harm or the potential for harm to that person and/or

involved others (including oneself). By making avoiding or mitigating harm the primary focus, this will likely overlook what other needs these individuals might have and may assume that protection from harm overrides other concerns - an assumption that can be challenged since people often assume the risk of harm(s) in order to pursue something of importance to them. In contrast, a focus on caring for the individual and her hope helps to ensure that the needs of the other are kept in the forefront and will allow these needs to direct the actions of health care providers (this will be explained further in Section 4.4).

Creating a supportive space within which patients can determine, share, and discuss their hopes may be one way of addressing the vulnerability associated with hope. However, creating this supportive environment for patients may be difficult to do and will require changes in the way health care is usually approached and delivered. The following description of Darcy Lyn's interactions with her oncologist and her family doctor helps to demonstrate both what needs to be changed/addressed and what can work with respect to patient hope. It also demonstrates vividly how a hope that is of great importance to a patient can be threatened by input from a particular individual, primarily because that hope is tied to the type of (medical) care and support this other person has to offer.

Darcy has lymphoma, but has responded well to treatment and will soon be discharged from the hospital to continue her chemotherapy treatments on an out-patient basis. She has been told by her family physician that her prognosis is good and she is hopeful that she will be able to beat her cancer.

The day before my release, Dr. Barnes [the oncologist] came in early to see me because he had to leave town for a few days. He sat on my bed, only the second time he did so,

and after he examined me we spoke about the chemotherapy. I would receive treatment in his office, located in the hospital complex... We spoke some more about chemo, which I felt was pretty tolerable, but to my surprise he reacted oddly. He stood up and said, "If you think this is manageable, wait until you have a bone marrow transplant!" I looked questioningly at him. "You'll be so full of drugs—really sick. You won't thank me then." (I had thanked him earlier for saving my life.) He abruptly left.

I sat in my bed confused, scared, and hurt. What had I said? Why a transplant? Had I crossed a line with him? Dr. Douglas [her family doctor] came in to find me in this emotional muddle. "What's the matter, Darcy?" he asked and quickly came over and sat by me. I told him what had passed between Dr. Barnes and me; after 20 minutes of hand-holding and explaining why I probably would not need a bone marrow transplant—I was responding so well to this chemo—I cheered up. (Lyn 1994, 27)

In this example, we are reminded of the vulnerability of patients to negative, off-hand, even well-intentioned (but unexplained) comments from their health care providers. By not explaining to Darcy that he wants her to be prepared for the possibility of a bone marrow transplant, despite the low chance that she would need it, the oncologist effectively dashes Darcy's hope that things will go well upon her discharge. The oncologist's desire to *protect* Darcy from being upset in the future if a bone marrow transplant is required has the effect of unsettling her completely now.⁶ The time taken by her family doctor to more fully explain what is going on and to do "damage control" helps to comfort Darcy and to restore her hope. The *care* displayed by her family physician at various points in her treatment and recovery is mentioned a number of times in Darcy's account and is cherished by her.

⁶ One could also see this as the oncologist protecting himself from potential recrimination in the future if Darcy does need to have a bone marrow transplant.

If health care providers are to address patient hope in an ethical fashion, then (among the other changes that will be discussed in this work) there is a need for health care providers to acknowledge: a) the vulnerability that accompanies the hope(s) of patients; b) that this vulnerability can take different forms - three were described above; and, c) that exacerbating, taking advantage of, or ignoring these various vulnerabilities can affect the ability of patients to hope and can even damage the patient-health care provider relationship, thereby making future hope work difficult and perhaps even undermining the effectiveness of medical treatment. (Recall the benefits of hope listed in Chapter Two.)

4.3: Thinking about Relationships and Ethical Approaches

I suggested in the introduction to this chapter that two points would arise from the discussion of vulnerability and hope - namely, the central role of relationships for hope would be further highlighted and that this would challenge traditional ethical approaches to provide adequate resources for analyzing and providing guidance with respect to patient hope. The goal of this section is to further develop these two points and, in turn, to motivate my move to a care ethics framework for situating this investigation of patient hope.

A thread that was started in Chapter One - that relationships are a key aspect of hope - has now been brought to the forefront in the discussion of vulnerability. Understanding vulnerability with respect to hope entails understanding how the support or lack of support by others can greatly influence the ability of an individual to discover and sustain hope. In the health care context, it is obvious that the relationships that exist and

are created between health care providers and patients must be examined in terms of their effects on patient hope (as well as the broader relationships or connections that shape and determine the context for these interactions). As I discussed above, given the nature of the relationships that are formed between patients and health care providers - ones in which patients often will have relatively less power, less control, and less information about their illness or injury - patients may (and likely will) be particularly dependent upon and vulnerable to what health care providers say and do in terms of both their ability to hope and what they hope for. As such, exploring the moral dimensions of these relationships with respect to hope seems particularly important. But what form should this analysis take?

One may be tempted to turn to the traditional or standard ethical theories to pursue this investigation. Indeed, there are a variety of ethical theories and ethical approaches, such as Kantianism or consequentialism, one could utilize to (try to) identify problematic assumptions and/or practices with respect to hope as well as to work out what the appropriate conditions for hope in health care should be. But not all ethical theories are equally capable of doing this type of moral work; that is, what is required for this investigation is a normative framework that is equipped to sort through and deal with the ethics of relationships. And, in particular, the framework must be able to provide insight into how best to structure, conduct, and evaluate relationships between individuals who are not equal. Further, as I argued in Chapter Two, talk of duties with respect to promoting hope or even fostering conditions for hope seems inappropriate and does not lend itself well to an investigation into the role of hope in health care. Recall that I

defended the claim that the language of responsibility is an improvement over the language of duties. Talking about responsibility with respect to hope allows discussion of shared responsibility among health care providers (and others) for patient hope, does not fall so easily into creating boundaries between individuals in terms of an emphasis on “rights and obligations,” and is more able to address emotions and feelings. Thus, the normative framework chosen must also be amenable to this shift in language. As Susan Sherwin argues:

Each theory has a definite appeal in a certain range of cases. Some problems seem to best fit the frame offered by consequentialist theories, others fit more comfortably in frameworks offered by deontological theories; still others seem to evoke appeals to an ethics of care. The reason, I believe, is that each sort of theory helps to make clear certain dimensions of the subject that may be inaccessible when using other approaches. (Sherwin 1999, 202-203)

The claim I will defend shortly is that care ethics “helps to make clear” the various types of relationships that influence patient hope in a way that the other ethical theories do not. Another way to explain this claim is to consider what each ethical theory takes to be the moral domain or what it places as central in its analysis.

As I stated at the outset of this project, little has been said about the ethical aspects of hope; hope has not often been considered worthy of the “center stage” in standard moral discussions. I believe part of the reason for this lack of attention to hope (and other emotions) can be found in understanding the underlying paradigm upon which theories like deontology and consequentialism, despite their differences, operate. This paradigm tends to assume that the best moral decisions are typically made from a disinterested and

disengaged point of view on the basis of reason by following or applying certain universal or codifiable principles.⁷ And, for the most part, these theories have tended to abstract away from the particularities of each individual to determine a generic feature that individuals or persons have, such that one can determine who counts as worthy of consideration when making moral decisions. (For Kant, this distinguishing characteristic is the ability of persons to reason.)

The upshot of this paradigm for circumscribing the moral terrain is that emotions and feelings should be mistrusted, or at least utilized cautiously, for they could lead a person astray in her ethical decision-making. This renders emotions and emotional considerations as potential “pollutants” in morality that dispose us to overlook the moral insights that can derive, for example, from our emotional connections to others. Further, in focusing on what enables each person to count (or not) for moral consideration, the traditional theories have been criticized for not being able to take proper account of the different relationships and contexts within which people live and work. By assuming that individuals are equal and that “each counts for one vote” (as claimed by basic utilitarian theory), these approaches tend to ignore the ways in which people are interdependent and, hence, how this interdependence should factor into our moral decisions. As Robin Dillon

⁷ Walker offers a similar description (and critique) of the form of the standard moral theories. For example, she states that: “While most feminist criticism has gone to the content of dominant moral theories, these theories also share a quite specific *form*. This form represents abstraction, generalization, and uniformity as the normal form of moral consideration...the theories this model requires [are] *code-like* theories...The picture of morality as a *compact, impersonally action-guiding code within (or for) an agent* results from a powerfully restrictive set of assumptions of what morality is.” (Walker 1998, 52-53; author’s emphasis.)

summarizes in her discussion of care and respect:

...(1) What matters about each of us is not (only) some abstract generic capacity but the fact that we are specific concrete individuals...(2) It is a morally significant fact about us that we each have our own way of looking at ourselves and the world....(3) Another of our morally significant features is that we cannot be entirely independent and self-sufficient, for we have needs and wants that we cannot satisfy on our own. (Dillon 1992, 73)

Thus, while the standard approaches to ethics do “help to make clear” certain features of the moral terrain (such as the consequences of actions), it appears that employing an ethical approach or framework that works within a different paradigm will be necessary in order to better meet the requirements listed above for an investigation into the role of hope in health care.

What is needed is an ethical theory that begins with “people’s engagement with others” (Tronto 1993, 178) and takes as its starting point the relationships that exist between persons who occupy various roles or positions. Care ethics recognizes, and argues for, the moral importance of the three features of human life described above by Dillon. And, by focusing on the particularity of individuals and their relationships of care, care theory creates space for attending to our emotions; it can also work through how our moral decisions both affect and are affected by our emotions and emotional connections to others. This is not to say that no insight(s) into the role of hope in health care can be gained from traditional approaches to ethics, but that the ethics of care has the most appropriate “tools” for this investigation. However, not just any theory of care ethics will do; as I will defend in the next section, feminist versions of care ethics are better able to

critique and evaluate relationships of care, especially ones of inequality. These latter versions of care ethics do not fall victim (as easily) to criticisms of valorizing care above all other ethical considerations and of accepting current, frequently distorted, constructions of caring relationships.

4.4: Feminist Care Ethics

Further evidence for the claim that feminist care ethics is most appropriate as a framework for this investigation is now warranted. Providing this support involves first understanding what feminist care ethics is; its description will reveal the merits of this approach as well as its applicability for thinking about the role of hope in health care.

Care ethics provides a conceptual framework that makes vast amounts of caretaking and caregiving activity appear in theory as they are in life--central and indispensable to the continuance, and many goods, of human societies. Caring labors include ministering to the needs of young and old, sick and dying, frail and dependent, as well as securing and reproducing through paid and unpaid labor many basic conditions of life for legions of fully able persons. The lens of "care" magnifies questions about the distribution and recognition of this socially vital labor: Who cares? (Walker 1998, 77-78)

In this short summary of care ethics, Margaret Urban Walker identifies some of the key features of this approach - ones that make it a valuable framework for investigating hope. First, care ethics focuses on a type of human labour that is largely overlooked, namely the labour of care and caring for others (and for oneself). In this respect, the ethic of care makes an important contribution to our understanding of morality. As Alisa L. Carse and Hilde Lindemann Nelson (1996) point out: "[T]he ethic of care...captur[es] certain

features of our moral lives that other, more standard approaches to morality underplay or ignore.” (19) Since a care perspective is able to reveal and assess various forms of caring labour, it seems a natural fit with the investigation of hope that I am undertaking in this project. The “lens” of care draws our attention to the ways in which patients and health care providers interact - not primarily out of the typical concerns about rights, autonomy, truth-telling (although these can play a role in caring labour as well as patient hope) - but out of concern for the ways in which care is given and care is received.

Second, in focusing on this form of labour, a number of related questions arise as to: Who cares? For whom? What care is provided? Is this care appropriate? From a feminist perspective, these questions are critical for revealing current patterns of care within which women in the range of social positions as well as men in the working classes and men of colour do a disproportionate amount of, often unpaid and underpaid, care. This perspective further attends to the power imbalances that are common to many caring relationships and addresses how these imbalances can affect care. While I focus primarily on patients and health care providers in this study, these questions about who gives care to whom and how the care is offered and received are all relevant to considerations of the role of hope in health care. As the earlier discussion of vulnerability demonstrated, being able to identify how relationships with others may affect patient hope allows one to challenge and to work toward changing problematic assumptions about and practices of care that relate to this emotional attitude.

To expand a bit further on what a feminist perspective can bring both to the ethic of care and to the investigation of the role of hope in health care, I turn to Susan Sherwin

who states that:

[a] principal task of a feminist ethics of health care is to develop conceptual models for restructuring the power associated with healing...It is important to clarify how excessive dependence can be reduced, how caring can be offered without paternalism...(Sherwin 1992, 93)

Many feminists agree that oppression is wrong in any of its forms and that oppression should be eliminated from society. As such, feminists ask questions about who has what power, who has particular resources and who does not, as well as who makes decisions and for what kinds of reasons. These questions are important as they encourage us to consider the various relationships within which people are embedded and the choices these individuals can face and are sometimes forced to make as a result of being in these relationships. Different forms of social organizations, policies, and systemic features that put pressure on, shape, and create these various relationships and choices can also be examined. In other words,

...from a feminist perspective, the relevant concrete details to be considered in our ethical deliberations include the political or power relations of the persons who are involved in or who are affected by the practice or policy being evaluated. (Sherwin 1996, 52)

These questions raised by a feminist perspective are directly relevant to the role of hope in health care, especially in combination with a care perspective. Since health care providers, on balance, have more power than patients, one needs to ensure that this power is not increased by taking something away from patients. In this case, what should not be

taken away from patients is their ability to discover and sustain their hope(s);⁸ and yet, this is easier said than done when one takes into account the various forms of vulnerability connected with hope. Further, from this perspective, one can (begin to) trace out and consider the ways in which, for example, cutbacks and policy decisions affect the care health care providers are able to offer to patients as well as the related implications for meeting patients' hope needs. In the following section, concern about the exploitation of care-givers will pick up on and extend this aspect of the care ethics framework.

Third, the connectedness and interdependence of individuals is recognized in feminist ethics of care; indeed, this is a central tenet of this approach. It ensures that the particular people who are being cared for and those who are doing the caring are kept in the forefront.

An adequate grasp of the moral contours of specific situations, especially as they concern other people and our responsibilities to them, requires an acute attentiveness to particularity and to the situation-specific nature of others' needs. (Carse and Nelson 1996, 20)

As mentioned above, this focus on the particular is in contrast to other ethical theories that abstract away from the concrete in order to develop (universal) guiding principles for action. A fundamental critique of these abstract theories is that they can end up overlooking important distinguishing features of individuals and situations that could

⁸As I explained in Chapter Two, this comment should not be understood as implying that health care providers can never question nor destroy specific hopes that patients have. Indeed, there will be some situations where it is necessary to destroy a hope - but, the key here is that there should be an effort to encourage the patient to find something else to hope for.

reconfigure both how the “dilemma” is framed and how its “solution” is formulated.⁹ As demonstrated by the patient stories I utilize in this project, there is a need to attend to each patient as a unique person and not in some formulaic or generic manner. When one reads these stories, a recurrent theme is found: patients want health care providers to acknowledge and address their particular suffering, problems, victories, defeats, and recoveries in a caring manner. It seems then that caring about patients as they go through these various experiences includes being concerned about the hope(s) of patients and the conditions for hope in health care - something which ethical perspectives, other than a feminist ethic of care, are less able to fully explore. In recognizing how people are connected and dependent on each other in a variety of ways, a care ethic further,

...underscores the moral significance of human interdependence, raising ethical concerns about aloneness, abandonment, neglect, and isolation--concerns that arise especially when we are in special states of vulnerability, as are those who are young, ill, frail, disabled, or otherwise in need of others' care. (Carse and Nelson 1996, 31)

⁹ Arguably, one of the best examples of this criticism is the debate over abortion. Frequently the debate is cast as one of determining whether the fetus is a person, since the guiding principle is that persons are afforded moral consideration and respect. Accordingly, if the fetus is a person, then it has rights or deserves to be protected etc. as other persons do. Yet, this focus on personhood as the distinguishing or guiding principle by which to determine the moral legitimacy of abortion overlooks the different reasons why women may want to have abortions, and, more importantly, ignores the fact that fetuses exist inside women's bodies. Attending to the particular circumstances within which women find themselves with an unwanted pregnancy casts a very different light on the abortion debate and on why it is/is not morally permissible and should/should not be available.

4.5: Feminist Ethics of Care - Tronto-style

Still, there are a variety of approaches one could take within feminist care ethics to situate this investigation of hope. As previously indicated, I have chosen to employ Joan Tronto's ethic of care. In what follows, I will explain her theory and its relevance to investigating the role of hope in health care, mindful of both its advantages and possible problems.

Tronto undertakes a sustained critique of the traditional ethics of care debate and demonstrates the political context within which both this debate and caring activities occur. She is careful to attend to the ways in which power relations affect our understanding of what care is, what the practices of care are and should be, as well as who is and should be providing care.

I [Tronto] spell out the concept of care and show how we think about care is deeply implicated in existing structures of power and inequality. As we currently formulate it, care functions ideologically to maintain privilege, but this function is disguised....I demonstrate that this notion of care is not only a moral concept, but a valuable *political* concept as well. Care helps us to rethink humans as interdependent beings. (Tronto 1993, 21; author's emphasis.)

Tronto's theory of care is useful because it emphasizes the importance of hearing and understanding the other person's needs and responding to these needs appropriately (this is discussed below). Its political basis is valuable as well for it helps to avoid,

...the danger of valuing caring relations separate from the economic, political, and social context in which they occur...[the] worry [is] that too little attention is paid within the ethics of care to the fact that social contexts can systematically deform caring relations and render caring ineffective. (Houston 1993, 115)

Accordingly, Tronto's approach to care forces us to look not only at patient and health care provider relationships with respect to hope (especially in terms of vulnerability), but also at the broader context within which these interactions occur.¹⁰

Tronto and Berenice Fisher define care as:

On the most general level, we suggest that caring be viewed as a *species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible*. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web...we insist that the activity of caring is largely defined culturally, and will vary among different cultures...caring [i]s ongoing. Care can characterize a single activity, or it can describe a process. (Tronto 1993, 103; author's emphasis)

This is a very broad definition of care which casts its net far beyond intimate relationships.¹¹ An advantage of this definition is that it demonstrates that much of the work we do can be viewed or described as caring labour and that care can involve people as well as our societies and our environment. Since I am limited to investigating the role of hope in health care, I will not be able to take full advantage of this broad understanding of care in this project. However, I do appreciate how this definition of care encourages me to imaginatively explore different ways of making changes to the way that health care is

¹⁰ For example, consider the time constraints placed on caring activities by personnel cutbacks and how this might affect the ability of health care providers to identify and respond to a patient's hope needs.

¹¹ Tronto's theory thereby avoids the common criticism of many ethics of care theories, namely that they hold up one relationship of care as a moral paradigm, such as the mother-child relationship. The charge is that this narrow focus distorts how care is and should be understood over a variety of different relationships; as such, these approaches to care ethics seem to validate self-sacrifice and constant care. (See, for example, Hoagland 1990, Tong 1993.)

organized and delivered in terms of its effects on patient hope.

But, what does it mean to “care” and to “care about patients and their ability to hope”? How should health care providers go about this caring labour? Tronto describes four different aspects of care: caring about, taking care of, care-giving, and care-receiving.¹² These four aspects “are analytically separate, but interconnected” (Tronto 1993, 106) and important facets of care; each is relevant for understanding the ways in which hope’s role in health care can be attended to. Tronto suggests that the ideal of care would be for these four aspects of care to be fully integrated and fulfilled well; however, she does acknowledge that, in practice, this ideal will be difficult to achieve. The four aspects of care may not be present in each situation of care nor will/do they necessarily follow each other in the order I describe them below. Before I turn to these descriptions, it is important to note that, in the following, I will be discussing the four aspects of care in terms of what each implies primarily for the role of health care providers, but also for others involved in the care of patients (such as hospital boards, administrators, etc.). However, this “slant” on the discussion is not intended to ignore the role of care-receivers nor to suggest that these individuals are not active participants in the different aspects of care (see, for example, the care-receiving aspect of care described below). One of my main reasons for using Tronto’s theory is that her breakdown of care into its four aspects is of great assistance in further understanding and fleshing out what the responsibility to foster conditions for patient hope should entail and I therefore want to emphasize these points

¹² The following descriptions of these four aspects of care and the related responsibilities rely heavily on Tronto’s work; see Tronto 1993, especially 106-108 and 127-136.

below.

Caring about involves recognizing that a need exists, that care is required, and that something should be done to meet this need. Yet, whose needs are recognized and what these needs are taken to be can be shaped in various ways, for example, by the society in which we live and by what our position/role is in that society. In terms of determining patients' hope needs, it is often the case that physicians (in particular) and patients do not come from similar socioeconomic, gender, ethnic, racial, and (dis)ability backgrounds and, as such, it would seem physicians should be cautious in automatically assuming that they know what the hope needs of their patients are. With respect to what "should" be hoped for by a particular patient, the physician may not know what is valued by this patient or what this patient's goals are nor what resources are available to support her hope (three things that can affect what is hoped for), especially if the physician and patient differ in one of the aforementioned respects.

This aspect of care thereby requires attentiveness on the part of those in a position to provide or offer care. In other words, there is a moral responsibility to consider what needs others might have and to acknowledge these needs when present. I argued earlier that health care providers have a responsibility to foster conditions within which patients can discover and continue to have hope. This responsibility fulfills this first aspect of Tronto's approach to care; that is, a need to attend to patient hope (as attested to in patients' stories) has been identified and it is has been determined that something can and should be done by health care providers to meet this need. Yet, while the general nature of this responsibility, "the fostering of conditions," draws attention to patient hope, it does

not tell the health care provider specifically what to do. Determining what this responsibility entails in given situations will be guided by the other three aspects of care.

Taking care of, as a second aspect of care, involves the individual who has assessed that there is a need to be met taking some responsibility for this need. This responsibility includes deciding that something can be done to meet the need, considering various options, and determining to take action. By extension then, taking care of requires care-givers to take seriously the implications of the choices they make about which action(s) to pursue and may place some expectation on them to find ways to meet the caring needs of others, despite apparent constraints or limitations of alternatives. Basically, the responsibility to “take care of” boils down to finding an appropriate way to (provide) care in a particular context and includes bringing together the money, resources, and people etc. that can make care happen. Properly attending to the needs of others will most likely give some direction or clues about what types of actions may be best and can thereby inform this aspect of care. Taking care of that fails to consider various alternatives for or assumptions about care makes it more likely that an inappropriate action for meeting a patient’s hope need may be pursued.

An example of this point is found in a study that investigated the way hope is talked about and understood by American oncologists.

The interviews [with 51 oncologists in Harvard teaching hospitals] suggest that for many oncologists “hopefulness” appears to be grounded primarily in the biomedical dimensions of their work. Caring is conveyed through the treatment process, through offering therapeutic options and

holding out hope for the development of new treatments on the cutting edge of medicine and technology. (Good 1990, 74)

Based on these interviews, Mary-Jo DelVecchio Good concludes that the common approach taken by oncologists for providing care and hope for patients is primarily based on medical interventions, technologies, and future developments in these areas. While this approach to care - care as treatment - is fine to a certain extent, this form of “care” will not necessarily meet all of the hope needs of patients and may even distort what these needs are perceived to be. Indeed, if the hope for cure or for the next treatment is all that is discussed by oncologists with their patients, other hopes in terms of quality of life issues and how to cope day-to-day with cancer may not be attended to and even overlooked. As Kay Toombs explains, this focus on medical interventions as care, or as the “only” form of care, can have negative repercussions.

Given the narrowness of this goal [the focus on cure], care that does not result in cure of disease is devalued and considered to be a less-than-optimal “fallback” position to be adopted only when all aggressive efforts to eradicate disease have failed. (Toombs 1995, 11)

...to the extent that medicine sees its primary focus as the diseased body (or, more specifically, the diseased body part), the task of addressing the psychological, spiritual, social, and cultural aspects of illness is - for the most part - considered peripheral to the more central aim of eradicating disease. Yet these aspects are an integral element of the illness experience and a major source of suffering for patients. (Toombs 1995, 12)

Toombs clearly describes how privileging care as cure and cure as medical treatment (using technologies etc.) can relegate other features of care for patients to the sidelines

and thereby render them less worthy. In turn, this understanding likely affects what are considered by health care providers to be relevant hopes for patients as well as the hopes patients “should” have. That is, there is a sense that patients should hope for cure as long as their oncologist hopes for cure and that this hope is the most important hope to have. As I have argued in Chapters Two and Three, this is not an approach to patient hope I endorse - taking care of patient hope requires a re-evaluation of practices of care that unduly narrow what can be hoped for by patients and effectively ignore what is valued by and is important to patients.¹³

The third aspect of care is *care-giving*. This aspect of care involves “the direct meeting of needs for care” (Tronto 1993, 107) and captures what is actually done (or not done as the case may be) to meet the need. This is perhaps the most obvious part of care as it is the “doing” of care. Tronto notes that this care frequently involves physical work and typically requires that one come in contact with the person who is being cared for.¹⁴ In other words, care is primarily (although not always) a “face-to-face” activity and involves both the person cared for and the person who is doing the caring actions.

¹³ Successfully identifying and changing problematic assumptions about and practices of care entails that those who receive care are heard from. This places a responsibility on those who provide care to ensure that care-receivers have input and places a corresponding expectation on care-receivers to voice their opinions about care (when possible).

¹⁴ But, as Sara Ruddick points out, even though care does often involve physical labour, this physical work should not overshadow the emotional needs of other persons. She explains that, “Most recipients of care are only partially “dependent” and are often becoming less so; most of their “needs,” even those clearly physical, cannot be separated from more elusive emotional requirements for respect, affection, and cheer.” (Ruddick 1998, 11)

This aspect of care extends the responsibility of care-givers from determining if something can be done to meet a need to ensuring that the care is given competently. Competence here means that one has the ability and skills to give the care and gives the care well according to the need. Tronto does acknowledge that,

Sometimes care will be inadequate because the resources available to provide care are inadequate. But short of such resource problems, how could it not be necessary that caring work be competently performed in order to demonstrate that one cares? (Tronto 1993, 133)

As I argued in Section 4.2, competent care with respect to hope would recognize patients' vulnerability and respond to it, for example, by ensuring that it is factored into discussions with patients. Both Bonnie's and Darcy's experiences clearly describe hope care that is not competently given because it ignores this feature of hope. Telling Bonnie that working towards regaining normal speech was "doomed to failure" did little to address Bonnie's hope needs and, in addition, Bonnie has the impression that the speech therapist is on her way to somewhere else more important. This impression clearly adds to the poor quality of care Bonnie feels she received. Darcy has a similar experience of poor hope care with her oncologist who frightens her with the future possibility of a bone marrow transplant and then quickly leaves the room. Fortunately, Darcy's family physician can provide competent care – care that addresses both her physical and emotional needs.

***Care-receiving* is the fourth aspect Tronto describes and it ensures the involvement of the person whose need for care was originally identified. It is only by including the person who is receiving care that it can be determined whether the actions taken were appropriate for meeting the caring need – and, importantly, whether the caring**

need was accurately framed.

...[P]erceptions of needs can be wrong. Even if the perception of a need is correct, how the care-givers choose to meet the need can cause new problems. A person with mobility limitations may prefer to feed herself, even though it would be quicker for the volunteer who has stopped by with the hot meal to feed her. Whose assessment of the more pressing need—the need for the volunteer to get to the next client, or the meal recipient’s need to preserve her dignity—is more compelling?...Unless we realize that the object cared for responds to the care received, we may ignore the existence of these dilemmas, and lose the ability to assess how adequately care is provided. (Tronto 1993, 108)

The moral responsibility Tronto ascribes for this aspect of care is responsiveness on the part of care-receivers. And, although Tronto does not fully explain this, responsiveness should be understood to cut across the other three aspects of care; in other words, care-receiving should not be limited to or thought solely of as the end-point of care (everything has been done, now let’s see how the person responds).¹⁵ Care-receiving can and should be integral to defining and redefining needs, choosing appropriate actions, and can occur concurrently with the actual care-giving. This aspect of care can thereby provide a means for setting and judging standards of care.

Clearly care-givers must attend to and be aware of the responses by care-receivers to each aspect of care. The expectation that care-givers will acknowledge these responses also extends to being “alert to the possibilities of abuse that arise with vulnerability”

¹⁵ Tronto’s use of terminology for this aspect of care (care-receiving and responsiveness) is somewhat problematic. Care-receiving does tend to be associated with or thought of as the final stage in caring labour, thereby implying that the care-receiver has been silent or passive until this point. However, despite my concern (and for lack of a better description), I will continue to use her terminology.

(Tronto 1993, 135) - supporting my earlier analysis of vulnerability and hope. With this aspect of care, Tronto establishes a “feedback loop” of responsiveness (care-receivers) and attentiveness (care-givers) as a part of what makes “good” care. Thus, we can see that the four aspects of care are and should be closely intertwined (recall Tronto’s ideal of care) and that caring will work best when care-receivers are able to express their needs without, for example, being made to feel guilty about requiring care (as guilt could silence a care-receiver from speaking up when care is not competently given).

Ultimately, Tronto suggests that the practices of care that develop or are developed provide limits, both implicitly and explicitly, for what is considered to be (ethically) acceptable with respect to identifying and meeting caring needs.

To call care a practice implies that it involves both thought and action, that thought and action are interrelated, and that they are directed toward some end. The activity, and its end, set the boundaries as to what appears reasonable within the framework of the practice. (Tronto 1993, 108)

The advantage to Tronto’s theory is that it can both: (1) draw to light and critique current practices of care; and, (2) provide direction for creating/establishing new practices of care, based on the identified caring needs (and this identification is in turn directed by her theory). Since all aspects of care, from identifying needs to acting on these needs to evaluating the response, are up for scrutiny, better judgements should be made about how to provide care. This will help to ensure that ethically appropriate and defensible practices of care generally, and specifically with respect to hope, are established.

Tronto does acknowledge though that care can involve conflict – conflict between the four aspects of care, between different care-givers, between different care-receivers,

and between care-givers and care-receivers. How these various conflicts are identified and resolved can impact on the care that patients receive as well as on patient hope. I have already argued that the responsibility for meeting the hope needs of patients does not fall entirely on one health care provider, but is shared by each provider to the degree that each is involved with the patient and is able to act. In a complex institution, such as medicine, it is clear that the care provided by physicians, nurses, and other health care providers could conflict and thereby create difficulties for “hope care.” It may be the case that the hope needs of a patient are identified by the physician who passes the duties onto another (a nurse) for fulfillment. In this exchange of caring duties, there may be disagreement about what should be done as well as what the hope need “really” is. An example of this type of conflict that comes readily to mind are those instances when a family has requested that a patient not be told her diagnosis of cancer and the attending physician has agreed. Nurses, who have to deal with questions from the patient about what is going on and get the sense that the patient is losing hope due to fear, may feel very uncomfortable not telling or lying to the patient and thereby may withdraw from her, exacerbating the patient’s sense of isolation and loss of hope. Clearly, the patient is not served well in this conflict between the involved nurses and the physician (and the family). As Tronto puts this more generally:

Nurses may have their own ideas about patients’ needs; indeed they may “care about” a patient more than the attending physician. Their job, however, does not often include correcting the physician’s judgement; it is the physician who “takes care of” the patient, even if the care-giving nurse notices something that the doctor does not notice or consider significant. (Tronto 1993, 109)

With respect to these conflicts (between care-givers), a distinction that Tronto

makes between who does what sorts of caring work becomes relevant. In her discussion of care as gendered, raced, and classed, Tronto points out that, "...caring about, and taking care of, are [typically] the duties of the powerful. Care-giving and care-receiving are [often] left to the less powerful." (Tronto 1993, 114) As suggested above, this separation of the aspects of care can be found in health care - caring about and taking care of are typically done by hospital administrators, physicians and others with the power to make decisions about what patient needs will be recognized and how these will be responded to.¹⁶ Minimally, these individuals set the boundaries for what care (in terms of programs, staff, etc.) can and will be offered to patients. On the other hand, nurses, physiotherapists, assistants, etc. are the ones who do (most of) the actual care-giving and are aware of the how the care is received. With this split between the aspects of care, it is much less likely that the discomfort, disappointment, and frustration with poor care - and even positive responses to good care - expressed by care-receivers will be heard by those who are in a position to make changes to practices of care. Unless there are mechanisms in place for feedback from the "frontline" care-givers and care-receivers *and this feedback is valued*, there will be little opportunity for those in a position to care about and to take care of to know about and change ineffective practices of care. And, as a result, the care-givers who have less power and do more of the hands-on care may be "forced" into providing care that they know will not meet the needs of patients and/or be expected to provide care that exceeds their means (in terms of time, skills, etc.).

¹⁶ And, of course, the decisions made at the level of health care institutions are constrained by government funding decisions demonstrating yet another level in the hierarchy of those who "care about."

This analysis of potential conflicts in care gives rise to a concern about the possible exploitation of care-givers - especially those with less power. Concern about exploitation is often raised as a criticism of care ethics, by both non-feminist and feminist writers, since this approach seems to legitimize exploitation by placing an emphasis on care and on meeting caring needs. The problem of (potential) exploitation will become particularly important in Chapter Six when I discuss the fostering of conditions in health care for hope and the corresponding responsibilities of health care providers. For example, the question can be asked as to where the line should be drawn, i.e., at what point can health care providers “stop” in terms of trying to foster conditions for hope? In order to set the stage for this later discussion, I will spend some time now determining what this feminist care ethics framework I have been describing and developing has to say about this concern.

As I understand it, there are two related forms of exploitation that must be addressed by care ethics: (1) since the care-giver ought to take into account the care-receiver’s response to the care that was provided, being aware of whether the original need was met and/or the existence of other needs seems to place an expectation of further action on the care-giver until all of the other person’s needs are met; and, (2) as discussed above, since the different aspects of care can be separated, this means that different people will often do different parts of the caring labour and this may result in situations where those who “care about” dictate to others how to “care-give” with, for example, little recourse for the actual care-givers (and care-receivers) to question these directions or provide input into decisions about what care will be offered. In other words, (some) care-givers may be exploited by care-receivers and/or by other care-givers with more power.

Yet, the force of this criticism is attenuated when one realizes that it relies (in part) on the mistaken assumption that feminist care ethics, including Tronto's theory, cannot draw upon the moral insights and guidance provided by other ethical theories.

This is not the case however. An advantage to utilizing a feminist version of care ethics is that feminism itself makes strong use of, for example, principles of justice. And, by drawing upon these principles within a feminist perspective, the task of defining limits for care and responding to this concern becomes much easier. As Carse and Nelson summarize:

If we are to protect against exploitative, abusive, demeaning, or otherwise unfair patterns of distribution and responsibility in our roles and relationships, we must have some way of reflecting critically on our roles and relationships and of determining which of the expressed needs, expectations, and demands with which they confront us are morally legitimate ones. And since we cannot respond to every legitimate claim on our care, we require a means of distinguishing between care we *may* give and care we *must* give. (Carse and Nelson 1996, 19-20)

It is a mistake to presume that care and justice are (only) applicable to different spheres of moral life, i.e., the private and public spheres respectively. Indeed, the principles of fairness and equality can play a key role in shaping our relationships with others and, in the same way, examining social justice issues from a care perspective can reveal the multiplicity of ways in which people are interconnected with each other and this insight can influence policy decisions.

The upshot of these latter points is that (the beginnings of) a response to the concern about both forms of exploitation of care-givers can be offered and is alluded to in

Tronto's theory. This response lies in drawing together the above-mentioned principles of justice with Tronto's commitment to a political feminist ethic of care. First, by making use of such concepts as fairness and equal consideration, this suggests that relationships in which the care-giver is taken advantage of, either by care-receivers or other care-givers, are problematic. A standard of fairness or equal consideration does not entail that each party must benefit equally from a caring exchange, but that the needs, vulnerabilities, and particular context of care-givers and care-receivers are each paid their due. In other words, simply because we are focusing on the caring aspect of relationships, this does not entail that care is exempt from other relevant moral standards.¹⁷ Some theorists have proposed a notion of relational justice, which calls for attention to all those involved in care in terms of respect, concern, and welfare, to meet the problem of exploitation in care ethics. (See, for example, Robin Dillon (1992) who describes the concept of care respect.)

As Carse and Nelson argue:

An acceptable account of relational justice must require respect, concern, and support for the well-being and flourishing of all parties within relational structures...justice prevails [in the context of care relationships] when each is attended to, each is heard, each is recognized, and-crucially-no one's welfare is ignored or dismissed...Within a care ethic, a decent solution to the problem of exploitation will refer us both to an examination of the balance of relational goods exchanged by individuals...and to the broader structure of the relational networks in which we live. (Carse and Nelson 1996, 23)

Thus, employing an account of relational justice in care ethics enables one to set limits on

¹⁷ See, for example, Tronto's comments on p. 154-155. She expands there on her claim that, "...care is a necessary, though not by itself sufficient, part of our account of moral life." (Tronto 1993, 155).

the care that must be given, both in terms of meeting the needs of others and in terms of what can legitimately be expected of those who provide care.

The last few sentences in the above quote connect nicely with Tronto's political and feminist commitments in her theory of care. As Tronto explains,

...only if we understand care as a political idea will we be able to change its status and the status of those who do caring work in our culture. (Tronto 1993, 157)

By analyzing care relationships in society, we are able to cast in stark relief where structures of power and privilege exist in society. Because questions of care are so concrete, an analysis of who cares for whom and for what reveals possible inequities much more clearly than do other forms of analysis. (Tronto 1993, 175)

Tronto argues that when care is properly understood as both a moral and political concept, it will challenge the ways in which caring relationships are currently formed as well as the ways in which society structures and (dis)values caring labour. Thus, in conjunction with an account of relational justice, it seems that Tronto's ethic of care has the appropriate tools with which to identify and work towards eliminating the exploitation of care-givers. Although this response is not fully worked out in her book, it seems clear that Tronto believes that once we start to value care as she describes it, this will initiate changes in how caring labours are distributed among and fulfilled by members of society.

Thus, the normative framework for investigating the role of hope in health care has been described and developed, noting both its advantages and potential drawbacks. In particular, the use of Tronto's theory enables me to draw attention to: (1) the current conditions for hope in health care as part of the broader practices of care; and, (2) the

relationships and interactions that shape and take place within health care in terms of their effects on patient hope. Provisions are now in place for working towards describing practices of care for patient hope that should be modified and/or established, especially with respect to the vulnerabilities associated with (patient) hope and the potential exploitation of care-givers.

4.6: Conclusion

The various forms of vulnerability associated with having hope and sharing one's hope with others have been explored, serving as a motivating reason for employing a feminist ethics of care as the normative framework for this investigation. Problems with traditional ethical theories were identified which make them unable to adequately address and evaluate the relationships that are an important part of hope. As such, this chapter has established a feminist ethic of care framework for investigating the role of hope in health care. Tronto's ethic of care ensures that attention is paid to both the interactions between patients and health care providers and to the structure and operation of medicine itself, as both relate to patient hope. This framework encourages consideration of the four aspects of care and the critique of existing practices of care on this basis. Importantly, through the analysis of Tronto's ethic of care, our understanding of the responsibility of health care providers has already been extended to include attentiveness and competence with respect to the hope needs of patients.

The remaining chapters will employ the feminist care ethic framework to complete two separate, yet related, tasks. In Chapter Five, I will explore some deeper problems

associated with the role of hope in health care. These problems include: the practice of “hope work” and the issue of false hope. The care framework will suggest new ways of understanding and dealing with these problems. Chapter Six will take up the task of fleshing out more thoroughly the responsibility of health care providers for fostering conditions within which patients can discover and continue to have hope. This involves exploring further the nature of this responsibility as well as the different ways in which conditions for hope can be conceived of and developed.

Chapter Five

From Hope Work to False Hope - Deeper Problems

PATIENT: Is there any hope, doctor?

DOCTOR: It depends on what you're hoping for.

5.1: Introduction

In this project, I have made use of modifiers such as “reasonable” and “legitimate” and “realistic” to describe some hopes that patients have. Yet, I have said little about what these modifiers mean nor have I said much about how these words establish certain categories of hopes for patients – those hopes which patients should hold and those that patients should not (i.e., these would be unreasonable, unrealistic, or false hopes). Ronald de Sousa observes that:

We often speak of a particular emotion as “reasonable.” What this means is not obvious. Sometimes it seems to mean nothing more than “I might feel this way too under similar circumstances.” At other times it reflects broader but equally inarticulate conventional standards: “It’s normal to feel this way.” Sometimes it is equivalent to “appropriate.” (Sousa 1987, 5)

As de Sousa suggests in his description of what “reasonable” might mean when applied to an emotion, there is reason to explore both what is said about an emotion as well as the context in which the emotion is held or expressed. In addition to social norms and expectations, the circumstances and the individuals present can all influence the emotions held and expressed as well as the evaluations of these emotions. Accordingly, this chapter takes aim at discovering what is considered to be “appropriate” or “reasonable” to hope

for in health care, primarily through the issue of false hope.

To begin this investigation, I will draw upon the results of an ethnographic study conducted by Anssi Perakyla. This study demonstrates that the typical patterns of conversation between seriously ill patients and health care providers circle around two primary outcomes with respect to hope - namely, the possibility of cure and/or palliation. Perakyla observes that one effect of these conversational patterns is a privileging of the medical view of reality and that what the patient should hope for, either cure or palliation, is linked to the patient's medical status. Two problems I identify with these conversational patterns are that: one, they limit what "appropriate" hopes are for patients; and, two, they fail to appreciate whether the patient's medical status should be the only grounds upon which hopes are based. Critically evaluating the results of Perakyla's study serves to remind us of some of the points made earlier in this dissertation¹ and will set the stage for introducing the issue of false hope. Perakyla notes that so-called "breakdowns" in conversations between patients and health care providers about hope do sometimes occur. And, in my opinion, these conversational "breakdowns" are one example of a situation in which health care providers may contend that a patient is holding a false hope.

Concerns expressed by health care providers about patients who have "false hopes" - as the primary example of inappropriate or unrealistic hopes - necessitates an exploration of what false hope is (or is not), what the basis for these judgements is, and, finally, whether these hopes should be changed. By assessing false hope from a care-giving

¹ Recall, for example, my concern about whether "space" exists in health care for hopes other than those primarily tied to medical outcomes (see Chapter Two).

and care-receiving perspective, new ways of understanding and approaching this issue can be gained. In particular, it will become clear that sweeping generalizations about patients and the merits of (false) hope tend to overlook important risks that accompany holding certain hopes as well as acting on these hopes. Likewise, focusing, for example, primarily on the medical evidence as to whether a hope will be realized can obscure other relevant factors in what is hoped for by patients. I will demonstrate that there are legitimate grounds upon which to challenge a patient's hope and/or the actions that stem from this hope, but that there needs to be more openness about and discussion of what these grounds actually are as well as what follows from contesting a patient's hope. By attending to how the hope needs of patients are constructed and constrained as well as responded to by health care providers, a number of (untenable) assumptions about and practices with respect to false hope will be identified. The feminist care ethics framework developed in the previous chapter will be of particular use in identifying and describing the tensions between what patients say they need and what health care providers believe these patients need and between supporting a particular patient's hope and providing adequate health (and hope) care for all patients. Ultimately, examining false hope will bring us back to how well or poorly certain practices of care (can) meet patients' hope needs.

Finally, I will show that changes in health, whether they are sudden or gradual, can affect how patients think about themselves. Appreciating this aspect of illness/injury is an important part of understanding and evaluating the "appropriateness" of what patients hope for. Patients are finding out who they are in the context of illness or injury and this (re-)discovery and/or (re-)definition of self can affect what is hoped for as well as how,

and to what extent, patients are involved in their own care. In order to provide good hope care for patients, health care providers need to be able to accommodate and appreciate this dynamic aspect of patient hope.

5.2: “Hope Work”

Anssi Perakyla undertook an ethnographic study of the conversational patterns between health care providers and seriously ill patients in three different clinical settings - a leukemia ward, a medical ward, and emergency.² Through her analysis of these interactions, Perakyla discovered how common and pervasive discussions about hope are between patients and health care providers (primarily physicians) in the leukemia and medical wards. In contrast, Perakyla found that discussions in emergency about hope were few. She suggests this is due to the brevity of the relationships and interactions in this setting; that is, in her opinion, health care providers tend not to commit to positive or negative outcomes in emergency situations until it is more clear as to whether the patient will stabilize.³ Thus, the following discussion of the results of Perakyla’s study applies

² Although this study took place within one hospital, which limits its generalization, Perakyla’s findings are worth exploring. To my knowledge, there is no comparable study of hope work with patients who have chronic illnesses or who are in rehabilitation. According to Laskiwski and Morse (1993): “Ethnography is based on the presupposition that groups of people share a cultural reality that results in their sharing beliefs and values. These beliefs and values are learned and are often implicit so that they are not readily apparent to those not integrated into the culture. Ethnography provides a method for making the implicit explicit, for interpreting the perspective within the setting and for communicating this perspective to those outside.” (144)

³ This observation by Perakyla helps to support the claim that the emphasis on or need for hope may shift between different clinical settings (I will address this more later in this chapter). However, if Perakyla was looking for conversational patterns that fit within

primarily to the medical and leukemia wards.

Based on her observations, Perakyla introduces the concept of “hope work” and defines it as an interactional process “leading either to the establishment of hope or to its orderly dismantling.” (Perakyla 1991, 409) In other words, hope work covers those conversational activities which have the effect of shaping what is hoped for (or not). These conversations also establish the relative roles of health care providers with respect to these hopes.

[H]ope work is a pervasive and important aspect of hospital life...the practices that assert hope and those that dismantle it serve the same purpose in maintaining the legitimacy and credibility of the medical version of reality. (Perakyla 1991, 409)

Overall, Perakyla observes that the standard conversational framework for addressing patients’ hope needs is limited primarily to considerations of curative and palliative hopes. Almost all of the interactions between patients and health care providers, and among health care providers themselves, that Perakyla judged to relate to hope aimed at slotting patients into one of these “hope categories.” Curative hope work focuses on the hope for cure and is closely tied to the patient’s medical status, i.e., whether the patient is responding well to treatment. Palliative hope work focuses on the hope for pain-control

the curative and palliative hope work structure she developed based on the other two wards, it may be that Perakyla overlooked comments that suggested hope to patients and their families in emergency. For example, comments such as, “It’s too soon to tell what the extent of the damage will be or how much it will affect the patient” (if these are made) would suggest that there is hope for the patient based on the lack of information that is currently available. It is reasonable to hold onto hope instead of, for example, falling into despair since it is not clear what will happen. Or, alternatively, until more is known, hope can come from placing one’s faith in the expertise of the emergency staff and the technology at their disposal and comments may be made to this end.

and on the comfort of the patient as her health deteriorates and/or when it becomes (more) clear that recovery is not possible. A third form of hope work is the conversational work that dismantles hope: when a transition from curative hope to palliative hope is required, a series of conversations take place that work towards changing what is hoped for by the patient and, to some extent, the medical staff. This dismantling or shifting of what is hoped for takes place in conjunction with changes in the patient's medical status and in terms of what the health care providers can or cannot do for the patient.⁴ As such, the identity and role of the health care providers is determined: when curative hope is present, the health care providers are the "ones in control who help the patient to get better," and, when palliative hope is present, the health care providers are the "ones in control who help the patient to feel better." (see Perakyla 1991, 420) The following two examples demonstrate typical interchanges between patients and health care providers that support curative hope and support the health care providers' role in realizing this hope.

The patient [a 30-year-old woman who had recently contracted leukemia] is talking about her job and at one point says, "if I get better." The doctor intervenes and says, "No, listen, it's always going to be *when* you get better." (Perakyla 1991, 413; author's explanation and emphasis)

The doctor, a nursing student, and myself [Perakyla] are leaving the room of a male patient in his early 20s. The doctor turns around and says to the patient, "You'll be cured. You have my word for that." The patient thanks the doctor for his encouragement. (Perakyla 1991, 413)

⁴ Perakyla does mention that the dismantling of palliative hopes can sometimes occur, but she not provide any examples of this form of hope work nor does she discuss whether the palliative hope would be changed into another hope or whether there would be no hope at this point. (See Perakyla 1991, 422 and 428.)

Ultimately, Perakyla demonstrates that hope work is part of the everyday practices in these two hospital wards and suggests that this hope work may be a necessary part of maintaining the validity and usefulness of health care procedures as well as part of establishing the role of health care providers as able to help. When death is an imminent possibility, the presumption that health care providers can help may be called into question and these conversational practices can assist in re-establishing this belief. For example, Perakyla comments on the “necessity” of hope work in the leukemia ward:

...leukemia is a severe disease, and its treatment is a very difficult and distressing experience for both the patients and the staff. Most of the symptoms that the patients suffer from are caused by the treatment itself....the chances of recovery from leukemia are not good...Consequently...[i]t is always possible to question the meaningfulness of all these efforts...If the parties concerned are willing to continue their work within the given medical frame, then it is necessary to continually reinforce that social reality and its plausibility. This is achieved by the hope work... (Perakyla 1991, 418)

In these situations, hope work functions to maintain the authority of the health care provider's judgement that treatment can help; this puts pressure on patients to agree and to place their hope in continued treatment. Hope work endeavours to give meaning to the treatments for both the health care providers (they are helping patients/being useful) and the patients (they are receiving help and getting better).

While I appreciate that patients will likely want to know or believe that the treatments they undergo have some value (as Perakyla suggests) and that this may be a critical part of maintaining some hopes, I am concerned that this treatment-focused form of hope work may overlook or ignore other important considerations in patient hope. Do

health care providers always need to be in control as this hope work constructs it?

Perakyla does not discuss whether she observed any conversations between patients and health care providers that suggested alternative framings of medical treatment and its relation to hope. It is possible, for example, that some patients may realize that they are approaching death, but "...continue treatment in order to satisfy their still hopeful physicians or family, or because they are carried along by the momentum of a routine course of treatment..." (Ruddick 1999, 346) As Ruddick suggests, there may be reasons, other than treatment or pain control, that influence a patient's decision to continue with a certain course of action and/or to hold onto a particular hope. And yet, the observed conversational patterns fail to address or acknowledge the high cost that continuing treatment may exact on the patient in terms of, for example, side effects, money, and a silencing of discussion about what the future may bring.

Thus, two problematic outcomes of this hope work can be identified: (1) there is little room available for exploring or holding other hopes if these do not fit within the curative or palliative framework - the conversational patterns that Perakyla observed do not seem to create openings for discussion about other hopes (such as hopes related to living day-to-day with a serious illness) or for determining whether a patient's hope needs are different than what might be assumed; and, (2) this hope work tends to minimize or even exclude considerations of the patient's values, experiences of her illness, etc. that ought to have a key role in evaluating and determining what patients "should" hope for. Although it may often be the case that what patients hope for does coincide with what their health care providers believe is reasonable or appropriate, the described hope work

structure tends to limit or, at least, it rarely initiates discussion about the reasons for holding certain hopes as well as how and/or what evidence supports this hope.⁵ The primary focus on the patient's medical status and how it does/does not change over certain intervals suggests that this information should be "the" determining factor in what is hoped for. As I argued in Chapter Two and will address further below, it is a mistake to assume that the medical status of the patient is the only or the primary information that can shape what a patient hopes for. Certainly for many patients, their medical condition and changes in it will affect what they hope for, but their hopes may also be affected by who they are, their previous experiences, their support networks, and their relationships with health care providers. For example, Perakyla describes a case in which a patient claims she is ready to die. The staff still believe that they can help her - they can at least offer palliative hope - and attempt to convince her of this. But she refuses to change her mind; she states that she has many problems, feels awful, and, on top of it all, her husband does not want her to come home. It is not clear whether this relationship is fractured or whether her husband can not adequately care for her; Perakyla does not describe (or suggest that) any other conversations that pursue this aspect of the patient's hope to die took place. (See Perakyla 1991, 423-424.)

Perakyla's observations suggest that this other information - such as the patient's

⁵ My contention is that increased openness, especially on the part of health care providers, for discussion about hope and openness about why one hopes for a particular state of affairs may be an important condition for fostering hope. Openness may assist in recognizing divergences between patients and health care providers about reasons for certain hopes and hopes themselves. It could also assist in attenuating the sense of conflict that arises when hopes diverge between patients and health care providers. I will explain this further below and in Chapter Six.

relationship with her significant other - is not always discussed with patients when hope work is done and the emphasis is on getting the patient's hope to change (based on her medical status). As such, there is a need for health care providers to be aware of the hope work they undertake and of the effects of these conversational practices. Perakyla further comments in her discussion of the results of her study:

It is part of the professional competence of doctors and nurses to know when and where and to what extent any type of hope work is required...However, there is a question of how thoroughly the staff members have recognized the pervasiveness of this phenomenon in their own activity...[Hope work] is not necessarily always recognized as a distinct activity by the people who are engaged in it. They may consider themselves as talking merely about "facts," when actually their speech acts are doing the work of reinforcing curative hope. (Perakyla 1991, 430-431)

In order to provide competent care for patients, in terms of what they hope for, health care providers need to be aware of how hope can permeate their interactions with patients and how the messages they give (intentionally or not) can affect patient hope. (This reflects some of my expressed concerns in the discussion about patient vulnerability with respect to hope in Chapter Four.)

Finally, Perakyla mentions in her study that there can be conflicts between patients and health care providers with respect to curative and palliative hope work. For example, a patient may resist the move from curative to palliative hope and staff members may resist a patient who moves to palliative hope when they still believe cure is a possibility. Perakyla observes that when these conflicts arise, there is an effort made to (re-)establish the medical perspective on what should be hoped for (which is in turn based on the

patient's medical status). For example, Perakyla describes one situation in which a patient refuses to give up curative hope even though chemotherapy had no effect on his leukemia and he was suffering from serious infections.

R [junior doctor] then asks me whether I have spoken to Mr. K...She tells me the following story about Mr. K: He's not willing to give up. The doctors, R herself and C, the junior doctor from the leukemia ward, have told the patient that there's very little that they can do to help him. C explained to him that there's no return to the remission stage; R herself has put it more bluntly. But Mr. K doesn't seem to want to know: "Surely we're not going to give up at this stage," he keeps saying. Both C and R feel that the best thing to do in this situation is to stop all medication so that the patient could go home, or at least minimize the amount of drugs. But Mr. K insists on having treatment. He doesn't seem to be interested in going home like the other patients. (Perakyla 1991, 424)

Little further detail is given by Perakyla about how this conflict, and others like it, are dealt with. Would, for example, trying to understand Mr. K's reasons for his "problematic" hope affect how the two doctors respond? Why doesn't Mr. K want to go home? Without more detail on why the patient, Mr. K, is holding onto his hope for cure, it is difficult to judge whether the health care providers should have attempted to intervene as they did, namely by bluntly telling Mr. K that he is going to die. However, an attempt to realign the patient's hope with medical evidence or with his medical condition is not *always* appropriate. (I will discuss this claim further later in this chapter.)

By exploring Perakyla's study of interactions between patients and health care providers, it has been discovered that basic patterns of conversation exist that have the effect of privileging the medical view of reality and narrowing the "legitimate" choices for

hope to that of cure and, failing that, palliation (at least in the leukemia and medical settings under study). I have argued that two problems arise from these conversational patterns - namely, that other, potentially legitimate hopes are not considered (by health care providers) and that the grounds upon which hopes are judged - the medical status of the patient - is insufficient. An interesting by-product of these observed conversational patterns is that, when these patterns are not followed, conflicts can arise between health care providers and patients about what should be hoped for, such as was described above with Mr. K. If patients switch between curative and palliative hopes too soon or too late according to health care providers, these hopes may be perceived as problematic and likely in need of change. The conversational patterns observed by Perakyla seem unable to accommodate patient hopes, such as the woman's hope to die described above, that do not fit the "expected" pattern where what is hoped for tracks the medical status of the patient. Accordingly it seems that if, for example, a patient continues to hope for a cure, like Mr. K, this hope will likely be regarded as inappropriate and "false." As such, this analysis of Perakyla's study brings us to the issue of false hope.

5.3: False Hope

Let me start with a bit of background to further motivate this discussion of false hope. During my clinical practicum (Fall 1998) in the oncology departments of both the Queen Elizabeth II Health Sciences Centre and the IWK Grace Health Centre, false hope was a topic that came up a number of times. The cases in which false hope was a primary concern were those cases where a patient was hoping for a cure for his or her cancer and

pursuing all available options to help reach this goal, whether these options were experimental, dangerous, and/or a regime of complementary therapies (akin to the case of Mr. K above). The physicians involved in these cases expressed the clear belief that the patient's hope for cure was false as the scientific evidence, the statistics for this cancer, didn't bear out such hope and, often, the condition of the patient (advanced metastases or lack of tumour response to chemotherapy or radiation) was such that it seemed highly unlikely that the patient would be able to recover. The question posed to me, as the bioethics student, was, "What do you do with a patient with false hope?" While a few physicians expressed some reservation about the extent of their involvement in shaping patient hopes, most indicated that they believed they should intervene and change what the patient was hoping for and, indeed, many often did attempt to do this.

Rethinking these experiences in light of the analysis of hope I have undertaken in this dissertation, a series of issues related to false hope can be identified. First, there is the presumption on the part of the oncologists that it is obvious what a false hope is. What struck me then and still strikes me now about these cases was how easy it was for those physicians to identify a hope as being false and to feel secure in that pronouncement. There wasn't much (if any) debate about whether it was a false hope or not; it was only a question of what to do about it. But, is there such a thing as false hope? Second, if false hope is a meaningful label for some hopes - and I will suggest shortly an alternate terminology - on what grounds is this determined and by whose judgement? This question helps to focus attention on the relationship between patients and health care providers, on what their relative training and experiences may be, and on the clinical context. As I have

argued earlier, differences between patients and health care providers may mean that these individuals evaluate and understand in disparate ways what can be hoped for; in the same way, I have also suggested that the context within which patients and health care providers interact may affect judgements about hope. Third, noticing these aspects of hope implies that there is a need to discover the reasons why the patient holds a particular hope as well as why the health care provider holds hers. Understanding these reasons could influence whether the hope is judged to be “really” false by a health care provider as well as the ways in which the discussion with respect to “changing” a patient’s hope may proceed. In my (albeit limited) clinical experiences, there was relatively little discussion about the reasons why a patient holds a particular hope and why the health care provider disagrees or hopes for something else. Fourth, there is the question of what interventions, if any, with respect to a patient’s “false” hope should be taken. Determining whether health care providers have a responsibility to intervene may, in part, rely on what actions the patient is taking/not taking with respect to the hope in question and the impact of these in/actions on herself and others. Intervention may also rely on a perceived future harm to the patient that could result from the hope not being met. The patient may experience great disappointment or despair if her hope is not realized and the sense is that this future negative emotional experience should be avoided because it could, for example, interfere with the patient’s ability to make the most of her remaining time. These comments suggest the overarching question that this section endeavours to answer - namely, why is false hope an issue for health care providers? In other words, what is at stake with false hope or with trying to ensure patients hold “legitimate” or “appropriate” hopes? The following

discussion will develop an answer to this overarching question beginning first with whether false hope is a meaningful label, building systematically towards answering the question about what health care providers should (or should not) do.⁶

5.3.1: Terminology

Is there such a thing as false hope? Some reject the claim that false hope exists:

There is no such thing as false hope. Any hope you carry is a real hope. If your hope is different from those around you, it simply means you're focussing on a reality that may not be their reality. Perhaps yours is based on something that happened in your past, or something you know about yourself that's unquestionably true. Perhaps what's real for you is informed by the accounts of others who beat the odds. You may see the same data everyone else sees, yet still choose to place your hope on the long shot. (Jevne and Miller 1999, 57)

Others who agree with this position further claim that, no matter what is hoped for, the positive benefits of having hope are still present; that is, the physical and psychological benefits of hope are still experienced by the person with hope, regardless of what she hopes for and the perceived "legitimacy" of this hope by others (see, for example, Simonton 1978). As we will see below, this claim about the benefits of hope *qua* hope for the individual is in dispute, particularly when what is hoped for has a low likelihood of being realized. However, the point to be made here is that disagreement about whether there is such a thing as "false" hope draws our attention immediately to the subjective

⁶ The following discussion will primarily address the "false" hopes of patients, not those of health care providers. I will return to the question of the hopes of health care providers in Chapter Six.

nature of hope. As Jevne and Miller claim: the person with hope may see reality from a different perspective than others and they argue that it is this difference which justifies the hope and makes the hope real for that person. In principle, I want to agree with Jevne and Miller's efforts to challenge assumptions about what counts as a "reasonable" hope and to expand the evidential grounds for hope beyond, for example, medical information. But does their claim mean that every individual's "reality" must be accepted as well as the hopes that stem from it? It seems likely that there are some hopes (and realities) that can, and even sometimes must, be challenged and efforts made to change what is hoped for. The subjective nature of hope does not mean that any and every hope can be legitimate. As such, there is more to the debate about false hope than denying the existence of this category of hopes would allow. But retaining the label of false hope for all hopes that are challenged seems rather limiting, given that the use of the word "false" implies that the challenged hope must be wrong. While I do want to allow that some hopes may actually be false (for reasons given shortly), it does seem important to distinguish these hopes from other hopes that may be challenged but are not obviously false nor wrong.

Accordingly, I propose the following changes in how hopes are classified and referred to: generally speaking, there are two main categories of hopes - those that are contested and those that are uncontested. Uncontested hopes are those hopes agreed upon by both patients and health care providers or are those to which health care providers are indifferent. There is no dispute about whether what is hoped for is "appropriate" or

“reasonable.”⁷ The contrasting category of contested hopes both better describes and captures those hopes that are considered problematic. Hopes can be contested on a variety of grounds as I will explain below, but contesting a hope does not entail that it must or will be changed. Using the label of “contested” should help to ensure that the subjective nature of hope as well as the subjective nature of judging the appropriateness, reasonableness, or legitimacy of a hope are kept in the forefront. It seems that claiming the hope is contested (rather than false) does not as quickly nor as easily dismiss the perspectives of both the person with that hope and the person judging the hope. And, as mentioned above, due to the oft-made association of something being false with it being wrong, shifting the terminology to talk of the broader category of contested hopes may also help to unsettle assumptions about what patients should (and should not) hope for in given clinical contexts.

Based on the definition of hope developed in Chapter Three, it seems that the most obvious reason for paying critical attention to what people hope for is that hope influences and affects how these individuals live their lives. As argued, hope is an emotional attitude that both affects what one attends to and how one acts. In the clinical context, there may

⁷ First, it should be noted here that I only claim that a health care provider needs to *agree* with what a patient hopes for for it to be uncontested, not that the health care provider needs to *share* this hope. The health care provider may not believe that she would hold that particular hope if she was in the same situation, but can still accept the hope as legitimate. Second, it is possible that a hope may be uncontested because it has not been shared with others; that is, the hope is uncontested because it is unknown (other than to the person with the hope). These are not the types of hopes that I intend to capture with these new categories. I am interested in hopes that are shared with health care providers. Third, simply because a hope is not contested by a health care provider, this does not mean that the hope is *uncontestable*. There are and should be moral constraints operating on what can be hoped for; I leave this discussion to another project.

be serious repercussions (harms) if patients hold onto and act on certain hopes and/or abandon other legitimate hopes; these harms need to be taken seriously and balanced with hope's potential benefits. As William Ruddick puts it, "We cannot assume that 'it is better to have hoped and lost than never to have hoped at all.'" (Ruddick 1999, 346); in other words, it cannot be presumed that hope *always* benefits the individual and, as such, there needs to be some way to evaluate and contest hopes. From the perspective of care ethics then, the issue of contested hope becomes one in which caring about patients and their hope sometimes means that health care providers will have to question and, if necessary, attempt to change a patient's hopes and/or related actions. Yet, as I will explain below, determining those cases in which this questioning and intervention is required is not a straight-forward task.

Completing this discussion of terminology, I do want to retain false hope as a meaningful label for some hopes. False hopes form a sub-category of uncontested and contested hopes; the number of hopes that properly fall into this sub-category is much smaller than often assumed. Hopes that are properly called false are those hopes for something that is impossible or inevitable. As my definition of hope clearly established that uncertainty is a key feature of hope (condition c), this is an obvious point. With false hope, the person is wrong about what is possible or likely to happen and therefore her hope is "not true" in this sense. I also include, as false, hopes that are for a state of affairs or event that is very close to being impossible or inevitable; of course, the important operator here is what constitutes "very close." In terms of what is hoped for, being very close to impossible or inevitable is intended to capture those hopes *most* would agree are either so

unlikely to come to pass (although still within the realm of possibility) or so likely to come to pass (forbearing some major unforeseen event) that a person would not be expected to say that she hopes for these states of affairs. In other words, the person might be more likely to state that she *wishes* for p or *expects* that p, respectively. Although the borders of what is considered to be very close to impossible or inevitable may be somewhat grey in certain cases, it seems reasonable to try to distinguish these false hopes from other contested hopes that are more open to debate as to their basis or merit.

5.3.2: Contesting and Judging Hopes - Delving Deeper

Perhaps the most familiar cases of contested hopes are those that arise in the context of terminal or life-threatening illnesses. As my experiences described earlier suggest, the contested hope typically is the hope for cure. The concern is that, with this hope, the patient is vulnerable to the promises of unscrupulous individuals with a supposed miracle cure or that the patient may be needlessly suffering the side effects of continued treatment. Or, the concern may be that the person is so wrapped up in trying to find a cure that she is failing to make preparations for her death. Quite clearly, the health care providers involved in these cases are concerned with the welfare or well-being of the patient and believe that the hope for cure and the in/actions taken on the basis of this hope may cause (or are causing) harm to the patient and potentially to relevant others such as her family. In order to promote the well-being of the patient (or family), health care providers believe they ought to try to change what the patient hopes for.

When described in this fashion, some may claim that it is not clear then why there

is debate about contested hopes - certainly health care providers are expected to help ensure the well-being of their patients and at least attempt to question or address the hopes and/or actions of patients that may not be in their best interests. But, one should not let the relative (even deceptive) simplicity of the above-described situation lead to a superficial exploration of contested hope and the series of issues I identified above. Some of the important subtleties of contesting certain patient hopes and their related actions can, perhaps, be best drawn out by considering what form this challenge may take in other clinical contexts such as rehabilitation (where it may be less obvious what "should" be hoped for). In this section, I am particularly interested in both revealing and critically examining the grounds upon which a patient's hope may be contested. I will demonstrate that challenging what is hoped for by a patient is context-dependent and that, for example, taking account of differences between patients, even those in the same (medical) situation, may change the evaluation of what is appropriate to hope for. (In the next section I will address the question of whether to intervene.)

Consider the delicate balance of hopes that a patient in rehabilitation may often try to achieve (likely with guidance and encouragement from health care providers and/or others who have been in a similar situation): this balance is between those hopes that can motivate her to work hard to recover as many abilities as possible and to make use of available aid and programs and those hopes that will end up hurting, disappointing, or even devastating the person when she realizes she won't be able to recover as fully as she would like. Setting one's hopes as high as possible, but minimizing the harm that may be experienced if those hopes are not realized is difficult. As Charles Krauthammer (a

physician with a spinal cord injury) argues in his commentary on Christopher Reeve's Super Bowl ad that told persons who are spinal-cord injured "a cure is imminent," if the hopes are set too high (i.e., for something that has a very small chance of happening) and these are not balanced by actions or other hopes that have a better chance of success, there are real harms that could result.

The harm [of the ad] is practical too [in addition to the emotional harm it may cause]. The newly paralyzed young might end up emulating Reeve, spending hours on end preparing their bodies to be ready to walk the day the miracle cure comes... These kids should instead be spending those hours reading, studying and preparing themselves for the opportunities in the new world that high technology has for the first time in history made possible for the disabled. They can have jobs and lives and careers. But they'll need to work hard at it. And they'll need to start with precisely the psychological acceptance of reality that Reeve is so determined to undermine. If I am wrong, the worst that can happen is that when the miracle comes, the nonbelievers will find themselves overtrained and overtoughened. But if Reeve is wrong, what will his dreamers be left with?
(Krauthammer 2000, 100)

Although Krauthammer does allow earlier in his article that this hope for a cure for spinal injuries may be what some people need to make it through the day, he is concerned that this not be the only hope that is held out to, especially, the newly injured young. He believes that these individuals are particularly vulnerable to the hope that Reeve is selling and, if they focus on this hope (and the reality it endorses), they will likely miss out on finding ways to live their life well with a spinal cord injury.

Clearly Krauthammer is concerned about the well-being of individuals with spinal cord injuries and contests Reeve's promoting of the hope for cure on this basis. And yet,

there is more to consider here than Krauthammer has identified - in particular, it seems that the potential harms of this hope may change depending on who the individual is. In Reeve's case, the costs of holding onto the hope for cure are relatively low (and therefore make it less likely that this hope should be contested). He has a supportive wife who devotes her time to caring for him, a substantial amount of money that allows for this care and enables him to have the "best" equipment and health care support, any progress he makes in his recovery is reported in the media and is cheered for by his many fans, and, further, the media attention gained from things like the Super Bowl ad help Reeve to maintain his celebrity status. Given his many resources and continued "employment" as a result of promoting this hope, it is unlikely that Reeve will suffer the types of harm that Krauthammer is concerned about.⁸ The individuals Krauthammer believes this hope for cure could harm (if these persons shape their life around this hope) are those who have fewer financial resources, may now find themselves unable to work and require retraining, and/or who may not have a partner who can be a full-time care-provider. Since hope can influence how one lives one's life, it seems clear that who the person is, what kind of life she has or could have, can and should affect judgements by others about what is reasonable to hope for in certain circumstances.⁹

Part of what Krauthammer is taking issue with with Reeve's ad is not only the

⁸ Of course, Reeve could still suffer emotional harm by holding onto this hope.

⁹ This observation helps to illustrate what is problematic about the conversational patterns that Perakyla described. Hope work follows a set path of what can be hoped for in the given clinical context and the only piece of information about the patient that influences the choice between promoting curative or palliative hope is the medical status of the patient.

hope for a cure for spinal cord injuries, but also the view of reality that this hope is based upon. Krauthammer clearly disagrees with Reeve about the chances of a cure being found in the near future and is unwilling to support this hope and the view of reality from which it stems. In effect, Krauthammer's critique draws out the "deeper" context that may be at work in judging hopes; if a health care provider, for example, endorses Reeve's hope, he or she is thereby also endorsing the individual's perspective on medicine and the state of the research with respect to a cure for spinal injuries. Thus, it may be that patients and health care providers sometimes not only disagree about what can be hoped for, but also about what the future holds, i.e., what view of reality accompanies or is implicit in hoping for particular states of affairs. As such, this draws out another way in which individuals who are trying to hope or to sustain their hope may be dependent upon the support of others, namely that these others agree, or at least allow, that a certain view of reality (or of the situation and its future possible outcomes) is plausible.

Yet, what is interesting here is that how one defines or understands "reality" can be shaped by who one is and what one's experiences and values are. Health care providers are trained to focus on medical information, to "see" reality from this perspective, and to make decisions on this basis; in effect, their view of the possible future for a patient will be heavily influenced by the relevant medical data. But patients may "see the world" differently and utilize different information to inform their "reality" and what they hope for. It seems that health care providers can challenge what patients hope for as well as the view of the future upon which this hope is based; accordingly, what governs what are or are not "legitimate" perspectives or realities will need to be addressed too. As I explore

other reasons for challenging particular patient hopes below, I will focus primarily on the individual or subjective nature of these hopes. But the types of reasons and objections raised will also apply to the “worldviews” implicit in what patients and health care providers perceive to be “appropriate” hopes.

A second, very common way of contesting what a patient hopes for is to claim that it is not a realizable possibility (this relates to condition (c) in my definition of hope). The claim is that the chances that what is hoped for will come to pass are low enough to warrant a re-evaluation of this hope and the actions taken to support it. This is the main basis upon which hopes are typically contested: there is a lining-up of the relevant (medical) evidence and a comparison is made between the various statistics and information to determine whether what a patient is hoping for meets some standard of what is reasonable or realistic given this information. It is this “test for the possible” that is most often used by health care providers to judge hopes and to explain why they are concerned about the legitimacy of a particular hope, believing that continuing to hold and/or act upon this hope could lead to harm - either in terms of future emotional hardship or as a result of the actions that are taken or opportunities missed. The claim is that if the patient “really understood the facts,” then this patient would not continue to hold onto a particular hope and would hope instead for some state of affairs that is considered to be more realistic (such as make the shift from curative to palliative hope which the doctors were trying to get Mr. K to do). Although it may sometimes be the case that a person has misunderstood the details of her situation, and thereby hopes for some state of affairs that will not come to pass, it is possible that in these cases the patient and the health care

provider interpret or understand the reasons and evidence for holding and acting on a particular hope differently. Thus, the deeper issues of who is judging what is hoped for and on what grounds, as well as the context of these evaluations, need to be more fully addressed.

There are two main points I want to investigate with respect to making judgements about what is a realizable possibility and contesting patient hopes on this basis: (1) the status of probability or possibility claims with respect to hope is not (always) immediately obvious - a privileging of medical evidence or statistics with respect to the legitimacy of a hope or the suggestion that hope “must” be tied to this evidence cannot always be sustained; patients and health care providers are differently situated in the health care context and their relative positions may sometimes provide different, and justifiable, interpretations of what is possible; and (2) the small chance of a hope being realized does not automatically entail that this hope is not legitimate or unreasonable - again, the context of the hope makes a difference to how the benefits and risks of that hope may be weighed. Let us look at each of these points in turn.

If one allows that there may be ranges within which hopes are considered to be appropriate, reasonable, or realistic, it is further likely that these ranges may be somewhat different between (and among) health care providers and patients, based on their respective experiences, understanding of medical information etc. In other words, health care providers and patients are differently situated with respect to illness or injury and their different perspectives can sometimes result in disagreements about what should be

hoped for.¹⁰ As Ruddick points out,

...physicians may tend to have hopes more sensitive to discouraging evidence than patients...Hence, physicians' ('probability') hopes for cure or remission may fade long before the ('possibility') hopes to which patients...cling... (Ruddick 1999, 356)¹¹

Some medical information does establish (relatively) clear boundaries as to what “objectively” will occur in terms of a patient’s illness or injury, such as the inevitable progression of amyotrophic lateral sclerosis - “[typically] no one lives longer than five years once the disease is contracted.” (Albom 1997, 10) But, knowing this “objective” information about ALS does not necessarily determine how a patient will respond to being diagnosed with this disease. For example, consider Morrie’s decision about how to live his life with ALS:

...when all this started, I asked myself, ‘Am I going to withdraw from the world, like most people do, or am I going to live?’ I decided I’m going to live—or at least try to live—the way I want, with dignity, with courage, with humor, with composure. There are some mornings when I cry and cry and mourn for myself. Some mornings, I’m so angry and bitter. But it doesn’t last too long. Then I get up and say, ‘I want to live...’ So far, I’ve been able to do it. Will I be able to continue? I don’t know. But I’m betting on myself that I will.” (Albom 1997, 21-22)

Further, the “hard” facts about some diseases or injuries can involve a measure of

¹⁰ I want to be careful here not to imply that the different perspectives patients and health care providers can have *necessarily* means that these individuals will disagree about what should be hoped for. Indeed, patients and health care providers do frequently agree about hope.

¹¹ Although Ruddick does claim earlier in his article that physicians and patients may have a “hybrid” set of possibility- and probability-hopes (see Ruddick 1999, 351), I believe his generalization here will often hold.

uncertainty when applied to individual patients as the statistics (with respect to prognosis, for example) are based on observations and studies of large populations within which there is typically a range of outcomes. Accordingly, it is not always clear how this group information applies to a given patient and to what that patient should hope for - will this patient be the one-in-one-thousand that recovers from a traumatic brain injury? Will this individual be the one with poorly managed diabetes who only develops fairly minor complications? As Rose McGee puts it:

The contention that hope is a product of the perception of the individual indicates that the use of the same set of facts to calculate probabilities predictably will result in varying degrees of hopefulness or hopelessness among different persons encountering similar circumstances. (McGee 1984, 35)

The point to be taken from McGee is that even if individuals agree on the evidence for and against a particular hope being realized (such as what the chances are for certain complications with diabetes), this does not necessarily mean that they will agree on whether the hope (that these complications will not arise) is reasonable. McGee provides support for this claim by discussing how both internal and external factors, such as an individual's beliefs about herself and her body and social cues from others, respectively, can influence how she evaluates the hopefulness of - as well as what can legitimately be hoped for in - a given situation.¹² Stephen Schmidt who has Crohn's disease has written an article entitled, "When You Come Into My Room," that describes under different category

¹² McGee's argument reflects a number of points I made in Chapter Four in terms of the vulnerability connected with hope - input from others as well as new information can affect what is hoped for.

headings the things that he would like his health care providers to know about him and that he considers are relevant to treating him as a person, rather than as *just* another patient with Chron's disease. The following are the six categories that Schmidt fills out:

When you come into my hospital room, you need to know the facts of my life; you need to know the losses of my life; you need to know my body; you need to know my heart; you need to know my mind and my spirit; and you need to sustain my hope. (Schmidt 1996, 512)

Judging or contesting what Schmidt hopes for would be difficult without spending at least some time determining how he understands his life with this chronic illness and the effects it has had on his life in terms of these various categories he describes. As Donald Capps sums up, “[w]hat we envision to be realizable is...profoundly influenced by what we understand ourselves to be.” (Capps 1995, 74)

And, as I have been arguing, patients and health care providers may sometimes “understand” themselves, each other, and the given situation in disparate ways. Certainly clinical data does offer useful information about a patient's prognosis, such as what level of recovery is likely from a particular injury and what treatments tend to work best, but, as mentioned, these data do not always determine what the course of the disease or the effects of an illness/injury will be for any individual patient. Each of us can probably think of examples of unexplained or miraculous recoveries; conversely, each of us can probably think of cases where persons should have gotten better or remained stable but did not. How does this information affect what is thought to be *realistic* or *reasonable* or *appropriate* to hope for from the health care provider's and the patient's perspective? Different responses to this question may be given based on what the illness/injury actually

is, the stage of the illness/degree of injury, and whether one is a health care provider or a patient.

If one accepts that hope is an emotional attitude, this implies that it has an information component. What is becoming apparent in the above discussion, as I question judgements about what it is possible to hope for, is that focusing primarily on medical expertise and information or privileging it over what the patient knows about herself and her illness or injury to determine whether a hope is legitimate is not always appropriate. In other words, the fallback position in situations where a patient's hope is contested should not always be to the judgement of the health care provider. Part of this tendency to privilege scientific information and the health care provider's perspective may result from the belief that those who are a "step away" from the situation may be able to make better judgements about what should be hoped for and/or the proper way to proceed. Since health care providers are thought to be less emotionally invested in what is hoped for as compared to patients, it is believed that what health care providers judge to be reasonable hopes should carry more weight. But, we should be careful about accepting this line of defence for privileging the health care provider's perspective for two reasons: (1) it is quite possible that health care providers will be (just as) emotionally invested in how their patients do as the patients themselves are - this investment would thereby affect the "reasoning" of health care providers as well; and, (2) it is not immediately obvious that those with interested perspectives necessarily make worse judgements than disinterested observers - indeed, it is quite possible that those who are emotionally involved will make better decisions because they will have a clearer understanding of the situation, who is

involved, and what the effects of various decisions might be.¹³

This brings us to the second point I want to discuss - how the relative importance of the likelihood of what is hoped for coming to pass may change depending on what the context is, including who is holding the hope and what the relative benefits and harms to them may be. Consider again the possibility of the hope for cure for spinal injuries being realized and Krauthammer's problems with Reeve promoting this hope. In Krauthammer's estimation, it is highly unlikely that a cure is "just around the corner" and that, if/when a cure is found, it will probably have the most benefit for those individuals who have been recently injured or may be injured in the future. Thus, the argument is that living one's life as if a cure is imminent will make one's life go less well than it could (or should) given the very small chances that a cure will be found; that is, Krauthammer is challenging the reality that Reeve is trying to get people to endorse. However, in other contexts, a low probability that what is hoped for will be realized does not necessarily mean that the individual should not have this hope. For example, although the chances that Bonnie would be able to regain normal speech were very small, her ability to make some sounds and words seemed to suggest that further progress could be made. And, given the importance of speaking to Bonnie's career and identity, it makes sense that Bonnie held onto this hope and continued working at her speech exercises. One relevant difference between hoping for a cure for spinal injuries and hoping to regain normal speech, despite

¹³ Support for this claim comes from both feminist care ethics (as described in Chapter Four) and feminist epistemology. See, for example, Richmond Campbell, *Illusions of Paradox: A Feminist Epistemology Naturalized*, (1998); especially Chapters Four, Six, and Nine.

their common low chance of success, is in the magnitude of the harm that could result if the hope is not realized. If Bonnie were not able to regain more speech beyond her current level, this would have been difficult for her to accept and may have had a significant impact on her career - but she still would have the ability to communicate with others (even if the level of communication is limited and less than Bonnie would like). The risk of or harm in pursuing this hope seems to be somewhat less than the harms Krauthammer describes if the hope for cure for spinal injuries is not realized.

Of course, making these judgements about the relative magnitude of harm, how this correlates with the possibility that the hope may or may not be realized, and whether a particular hope should be contested accordingly are not easy. Further, it is a mistake to assume that it is the *small* chance that a hope may come to pass that is always a (or the) determining factor in assessing what is reasonable to hope for. A fifty-percent chance that a person will be able to walk again seems pretty good and most would agree that hoping for this would be legitimate. In contrast, a fifty-percent chance that a child will be born with a severe disability may mean that some women choose not to become pregnant as they believe the risk is too great. Again, the context within which the possibility of a hope being realized is estimated, both in terms of the possible benefits and harms and the individuals in the situation, can have an impact on what is considered an appropriate hope and course of action.

As I have been claiming throughout this discussion, it is also possible to contest a

patient's hope based on the in/actions that follow from it.¹⁴ This aspect of evaluating hopes straddles both concerns about the patient's welfare and concerns about the resources available for supporting patient hope (a new reason for contesting hope that I will discuss more below). However, challenging a patient's hope, based on the actions she does/does not take or based on what actions the hope may rely on from others for its realization requires an important caveat - namely, there is a difference between challenging the hope and challenging the actions that follow from it. In other words, it is possible to contest the actions a patient takes and not the hope itself. Noticing this difference is important as it often seems to be the case that concern about the actions patients are/are not taking based on a particular hope becomes a judgement that the hope must be changed (the reasoning being, I presume, that if the hope is reasonable, then the actions will be too; but this does not necessarily follow).¹⁵

Again, the context within which a hope and its related actions are being evaluated needs to be taken into account. In rehabilitation, the process of recovery often is lengthy, tedious, and painful. For example, trying to maintain one's hope to walk again day in and day out and to pursue the actions that may help realize this hope will clearly be difficult. When a patient refuses to do her physiotherapy, part of the role of the health care provider will be to determine if the hope to walk again is actually lost, or should be altered, or

¹⁴ Recall my earlier discussion of the connections between hope and action in Chapter Three; see Sections 3.4 and 3.5 in particular.

¹⁵ Note that Krauthammer's argument is that the hope for a cure for spinal cord injuries should be changed (or not held) because the actions that "will" follow from this hope are harmful.

whether the person is just having a bad day and needs a chance to rest in order to face more physiotherapy.¹⁶ Being a good care-giver then means that an effort must be made to determine what the care-receiver's "real" or "true" needs are; even if the patient wants to give up hope, trying to encourage the patient to continue with her rehabilitation plan may be just what the health care provider has to do in order to promote the patient's well-being. Instead of the health care provider working to change the patient's hope to walk again, the health care provider may be able to suggest smaller, more realizable hopes that, when held in succession or focused on by the patient, will provide the motivation to continue and will help to achieve the more distant (and desired) hope to walk again. For example, Morse and Doberneck found that:

Hoping in the spinal cord-injured group was manifest as *working toward small incremental gains*...Attaining each goal required extraordinary self-discipline and the determination to achieve small and important goals [as part of working toward what is hoped for, namely increased mobility or walking.] This pattern was labeled, "*incremental hope*." (Morse and Doberneck 1995, 283)

The most common cases in which a patient's hope and her related actions are contested is when these actions will (likely) cause harm to the patient and/or related others. Physical harm is perhaps the easiest form of harm for health care providers to

¹⁶ This suggests another way in which health care providers can contest what a patient does or does not do on the basis of her hope: if the health care providers believe the patient has a reasonable hope, but the patient is not acting in ways consistent with this hope or if she is not participating in her care (at least to the extent she is able), then it seems the health care providers would want to challenge this lack of involvement. Indeed, it seems that part of the patient's role in finding and sustaining her hopes is that she *will* act on her hopes. Health care providers may sometimes have to push, even bully, patients to keep working at realizing what they hope for, but the expectation is that patients will act on their hopes.

identify and factor into their assessments of the appropriateness of acting on and holding a particular hope. For example, the severity of the side effects a patient experiences during her first round of chemotherapy in terms of nausea, infections, and headaches may mean health care providers are much less likely to support this patient's hope that a second round of chemotherapy will help her. Concerns about the emotional harm that a patient may experience when her hope is not realized can also be a part of contesting what is hoped for - trying to estimate this type of harm may be rather difficult. In addition, it may be possible in some cases that concerns about the harms of patients acting on certain hopes may or can be mitigated; this could thereby affect whether the actions taken and/or the hope are considered reasonable. For example, Kay's hope that she can continue to work as a physician despite having manic-depression may be of concern to some of her colleagues - what will happen to her patients if she becomes manic or depressed? The possible harm that could come to Kay's patients may suggest that her hope to continue working is problematic or unreasonable. However, anticipating the possibility that her illness could put patients in jeopardy, Kay has put certain safeguards in place: her supervisor and the head physicians always know about her illness and are able to talk to her psychiatrist if they have any concerns; they can also revoke her hospital privileges if necessary. These safeguards both help to ensure the safety of Kay's patients (and likely her own) and assist in supporting Kay's hope that she can continue to work. The point here is that health care providers may be more comfortable accepting or endorsing certain hopes of patients if the potential harms that could result from these hopes can be prevented or lessened in some fashion.

Considering other ways in which a hope can be contested based on its related actions will be useful. A hope may also be contested if it relies on: a) the expectation that others will act in ways that are illegal or morally impermissible (and these others are unwilling to commit illegal or immoral acts);¹⁷ or, b) depends on the resources of others or oneself that are not available. The availability of resources and the role of others in supporting an individual's hope suggest a further way in which a hope may be contested: if, for example, the chances are low that a patient's hope will be realized, it may seem to others that acting on the hope is not worth much effort. That is, others may believe that committing one's time to the hope or enlisting others to act on one's hope would be a waste of time and resources. In other words, there is a sense that there is a line between what does and does not seem reasonable to do in order to support a hope. Importantly, this line may shift depending on whether one is the person with the hope or a health care provider. This feature of contested hopes speaks primarily to the role of others in terms of what patients hope for - how far must health care providers go in supporting a patient's hope? Does this include providing all forms of treatment? What about emotional support? Is it possible for health care providers to support a patient's hope, but not the means to achieve that hope? While health care providers may be able to assist a patient in pursuing

¹⁷ One example of this would be the hope for physician-assisted suicide, if one knows that one's physician will not participate in this activity. However, holding onto this hope may not be wrong if, for example, the hope is utilized to work towards social change or to challenge existing laws (such as Sue Rodriguez did). Of course, the legal and moral constraints health care providers must work within will provide a basis for refusing to support particular hopes. In other words, it is possible for a health care provider to refuse to support a patient's hope due to the value system upon which the hope is based (such as with requests for genital surgery). I will not pursue this aspect of contested hopes further in this project and thereby leave it for future work.

her hope by providing emotional support and/or the practical means to achieve it, the amount of time or resources that acting on some patient hopes would require may be too great. Considering the role of health care providers in supporting patient hopes draws our attention (again) to the possible exploitation of health care providers in service of patients' hope needs (recall the discussion in Chapter Four, Section 4.5).

To understand this point, we can revisit the exchange between Bonnie and her speech therapist (see Section 4.2) and suggest a different spin on the situation from the speech therapist's perspective. Although the speech therapist tells Bonnie that she will never be able to talk "normally" again and consequently she will not spend time with Bonnie, it is possible to imagine the explanation or reasoning of the speech therapist working differently. For example, the speech therapist likely works with a number of patients in the rehabilitation centre and may have more patients to care for than she can realistically manage due to staff cutbacks. Given this situation, the speech therapist may recognize that she *cares about* all of these patients, but that she will have to make choices about who to *care for*. Since the likelihood of success with Bonnie is low, the speech therapist may have decided to spend her time with other patients who will likely benefit more from her assistance (and may require less time). Thus, one can see how Bonnie's hope to talk again may be contested by the speech therapist - not because it is impossible or highly unlikely - but because it is based on receiving support from the already overworked speech therapist.

Thus far then, we have learned that contesting a patient's hope is often not a straight-forward process as the grounds for making such a challenge need to be carefully

considered. Although there are cases in which it is clear that a patient's hope must be challenged - such as when the actions taken in support of a hope will cause harm - the above discussion has demonstrated that judgements about what are reasonable or appropriate hopes for patients to have need to be sensitive to the specific contexts for those hopes, including both an evaluation of the relevant medical evidence and an appreciation of who the patients are and what is of importance to them. Of particular interest was the revelation that hopes may sometimes be considered problematic because fulfilling these hopes requires resources that will exceed the support that can be offered by health care providers who have to make choices about who receives what care.¹⁸

5.3.3: When Should Health Care Providers Intervene?

Based on the above discussion, we have learned that there are cases in which contesting a patient's hope will typically be appropriate. I summarize them here: a) the hope is false or based on misinformation or a misunderstanding; b) the hope itself or the actions being taken on the basis of the hope will most likely cause or are causing harm to the patient and/or others; or c) the hope that the patient has is based upon expectations of health care providers and/or others which these individuals cannot and should not meet (for example, the hope that the hospital will give every treatment at the end of life may need to be addressed if the hospital has a policy about withholding and withdrawing medically unnecessary treatments). Beyond these three situations, it is not immediately

¹⁸ I will further discuss the issue of boundaries and limits to the fostering of conditions for hope in Chapter Six.

obvious why a patient's hope would be challenged. Yet, even if a patient's hope may legitimately be contested (for example, good reasons or evidence are given to demonstrate harm), does this mean that health care providers should intervene in what is hoped for? As I indicated in the introduction to this discussion of contested hope, the oncologists who challenged me to answer the question, "What do you do with a patient with a false (contested) hope?" felt that they should intervene when a patient's hope was judged to be problematic. But is intervention (always) necessary? In the following, I will discuss *some* important considerations with respect to intervening in what a patient hopes for and/or how she is acting based on this hope. Since I have argued that determining whether a particular hope is reasonable for a patient to hold is context- and person-dependent, it will come as no surprise that I argue that determining whether to intervene will also vary according to these factors.

As I understand it, there are at least four different options available to health care providers when they disagree with what a patient hopes for. They can: (1) do nothing about what is hoped for; (2) choose to discuss the hope with the patient in order to further understand the patient's reasons for holding this hope (as this may provide insight into the hope that would change the health care provider's evaluation); (3) try to change or shift what is hoped for by the patient (or at least suggest alternative hopes); or, (4) try to change the in/actions of the patient and/or put some safeguards in place in order to prevent or mitigate harm. Clearly, not all of these options may be available when a patient's hope is contested nor will each necessarily be pursued separately. For example, it may be that trying to discuss what is hoped for with a patient may result in the patient

changing what she hopes for or that the harms that may stem from a particular hope seem so great that both the hope and its related actions will need to be challenged.

Why would a health care provider choose not to question a patient's hope when it is considered problematic? It may be that the individual is functionally coping in her life, even with this inappropriate hope, and the health care provider does not believe that there is any immediate harm that will come to the patient as a result of having this hope. Given how intertwined a patient's hope is with her values and goals, the move to question a patient's hope should be balanced with the realization that intervening, even for the sake of clarification, may actually cause harm in itself. For example, questioning a patient's reasons for holding onto the hope for cure may make the person face her impending death or the permanence of her injury before she is able to cope with this information. It may also be that questioning or attempting to change what a patient hopes for could damage the patient-health care provider relationship, if the patient perceives this questioning as a lack of support for or insensitivity to what the patient is going through. Donald Capps comments that,

[o]ne reason we resent admonitions to be "realistic" [with respect to our hopes] is that we suspect that they are based not on intimate knowledge of ourselves, but instead on a knowledge of humanity in general or on some group or category of humans with whom we are being identified on the basis of age, gender, race, or cultural background. We feel that if the other person really knew us, in our own unique individuality, he or she would not be voicing these admonitions or would at least express them very differently. (Capps, 74)

As well, I would add that generalizations made about individuals based on illness or injury

can also affect what is perceived to be “realistic” to hope for and could negatively influence discussions with patients about hope. Alternatively, if handled well, talking openly and honestly with a patient about hope and possible states of affairs to hope for (the “imagining together” I discussed in Chapter Three) could strengthen the patient-health care provider relationship. Part of the health care provider’s decision to take action will have to consider how to best approach the issue of hope with a given patient.

It is also useful to ask whether it is necessary to intervene immediately. Even though a patient’s hope may be judged unreasonable, planning to intervene immediately may not always be appropriate and/or necessary. For example, it may be possible to “wait-and-see” how the patient’s hope does or does not change over a certain time frame. It may be better for a patient to realize that what she hopes for will not happen and to allow her the chance to begin the process of accepting this, before the health care provider attempts to question or change that hope. Part of caring for the patient and her hope may be in the health care provider realizing that she does not have to do something right away.

Further, appropriately acknowledging the uncertainty of what the future may bring may influence how the discussion with a patient about her hope is approached (if this is deemed necessary). As what is hoped for gets closer to the margins of what is impossible or what is certain to come to pass, it seems that the discussion about hope will also take on a more determinate tone. For example, if it is certain that a patient’s severed limb cannot be reattached, then one would expect the health care provider to convey this information to the patient. The health care provider would not want to continue to let the patient (falsely) hope that her limb could be reattached. Conversely, when it is very

uncertain as to whether an experimental treatment will work, one might expect that the discussion about hope would also reflect this uncertainty. Finding the balance between allowing that hope for success with this treatment does exist, but wanting the person to be aware that it may not work and to think about how she might deal with this loss of hope and find other things to hope for, could be the goal of the discussion about hope. It may also be appropriate at this point for the health care provider to suggest alternate actions or ways to support the hope and/or try to create safeguards to minimize potential harms. For example, if the patient does decide to try the experimental treatment, it may be reasonable to discuss with the patient possible points at which she would consider stopping this treatment - would it be severe side effects? Would it be an inability to continue meeting with her book club every two weeks? Would it make a difference if home care were available?

A final consideration I will raise here about the decision to intervene is whether the health care provider is trying to change the patient's hope because she feels guilty that she can not meet the patient's hope needs. This consideration turns on the health care provider examining her reasons for contesting a patient's hope and for wanting to change what is hoped for. Little is said in the literature about how health care providers deal with not being able to fulfill or help realize patient hopes. But it seems that assuming a hope should be changed because it can't be met may miss part of the message about how to care for patients and for patient hopes. As the examples I have been employing suggest, sometimes realizing the hope is not what is most important to patients. What may be more important is that others - including health care providers - actually hear what one is hoping for (and

is afraid of) and make an effort to understand what the experience of illness or injury is like for that individual. As Stephen Schmidt writes at the end of his article:

When you come into my room...
 [you need to] support my hope that tomorrow there may be
 new medicines
 that today you care deeply
 that you will do your best.
 When you come into my hospital room, promise me
 presence
 promise me a healing partnership... (Schmidt 1996, 512)

Schmidt is not asking his health care providers to always agree with what he hopes for, but is asking them for (competent) care that supports and recognizes the role his hopes play in his life - even if these hopes sometimes need to be contested and possibly changed.

5.3.4: Taking a Different Tack - Hope and Self-Definition

My analysis of contesting and potentially intervening in patient hopes is not yet complete. This section aims to extend our appreciation of the patient's perspective as this pertains to what she hopes for, whether she is able to cope with her illness or injury, and the likely connection between hope and the patient's attitude toward and participation in her care. I will argue that people change and continue to change as they learn "who they are" in the context of illness or injury. As this process of self-discovery or self-definition (or re-definition) takes place, what patients hope for may change. Sometimes these hopes will change rapidly from day-to-day and at other times these hopes may be difficult to sustain or will remain stable over a long period of time. Quick judgements about whether a patient's hope is reasonable or appropriate and attempts to intervene on this basis may

tend to do more harm than good if the involved health care providers fail to recognize that they can help patients to find ways to heal or to find meaning in suffering. Even when health care providers feel they must intervene in what a patient hopes for, they need to acknowledge that finding and sustaining hopes is a dynamic and interactive process within which their participation is part of the care they give to patients.

Consider again Morrie's comments about how he tries to live his life with ALS. In addition to what I quoted earlier (i.e., where Morrie states that sometimes he mourns and sometimes he is angry, but ultimately he tries to live each day well), Morrie states:

“Here's how my emotions go...When I have people and friends here, I'm very up. The loving relationships maintain me. But there are days when I am depressed. Let me not deceive you. I see certain things going and I feel a sense of dread. What am I going to do without my hands? What happens when I can't speak? Swallowing, I don't care so much about--so they feed me through a tube, so what? But my voice? My hands? They're such an essential part of me. I talk with my voice. I gesture with my hands. This is how I give to people.”

“How will you give when you can no longer speak?”
Morrie shrugged. “Maybe I'll have everyone ask me yes or no questions.” (Albom 1997, 70)

In this passage, we learn that, as his ALS progresses and he is left with less and less motor control over the various functions of his body, Morrie is concerned more about some of these losses as opposed to others. Although some may regard feeding tubes with dread, Morrie doesn't really care about this eventuality. Instead, he is concerned about how he will remain himself if he can't communicate with his hands and voice. Looking to the future makes it difficult for Morrie to sustain his hope that he can live each day well; and yet, when pushed, Morrie finds a possible solution that will help him to continue

communicating meaningfully with others and to continue to have hope - namely, he will get people to ask him yes or no questions. Finding ways to adapt as his body changes helps Morrie to retain the aspects of his personality and life that he believes are essential to who he is. These adaptations, whether they be relying on others for help or changing his perspective, are a critical part of Morrie being able to deal with the suffering that this illness brings him. What Morrie helps us to remember is that what is hoped for and the actions taken to support this hope are not static - although Morrie wants to hold onto his hope to live life well, the definition of what it means to live life well changes throughout the course of his illness. As Morrie himself says,

“I’m an independent person, so my inclination was to fight all of this--being helped from the car, having someone else dress me...But then I figured...*I am not going to be ashamed. What’s the big deal?*...I began to enjoy my dependency. Now I enjoy when they turn me over on my side and rub cream on my behind so I don’t get sores.”
(Albom 1997, 115-116; author’s emphasis and quotations)

Finding out that he could enjoy being dependent was a key way for Morrie to deal with the changes that ALS brought to his life. Yet, not all patients are able to accept or find joy in the changes they are forced to make as a result of an illness or injury. Some patients may discover hidden strengths while others are disappointed with the “self” that is revealed in illness, a self that may be less tolerant, more critical, and/or more needy than they would like to be. And, importantly, the lessons one learns about oneself may not be the same each day. A patient may be able to change and roll with what comes her way one day and not the next. As Kathy Charmaz points out:

Having a chronic illness means more than learning to live with it. It means struggling to maintain control over the defining images of self and over one's life. This struggle is grounded in concrete experiences of managing daily life, grappling with illness, and making sense of it. (Charmaz 1991, 5)

Good days are, of course, relative to an ill person's criteria and experience of chronic illness...On a good day, ill people have more opportunity to be the selves they wish to be...A bad day means intensified intrusiveness of illness, less control over mind, body, and actions, and limited choices about activities...Frustration marks a bad day and leads to fury, often at self. (Charmaz 1991, 51)

Caring for patients and what they hope for then is obviously not all about cure and/or pain relief as Perakyla's observed conversational patterns suggest; instead, it is about finding ways to assist patients in their struggles, both physical and emotional, with their illness or injury. Contesting patient hopes and trying to determine what is an appropriate or reasonable hope for a patient is only one way in which caring about and taking care of patients may proceed. If health care providers understand their responsibility with respect to patient hope as only requiring them to act when patients lack hope or hold an unreasonable hope, many other opportunities for helping to foster conditions within which patients may find hope and ways to heal will be obscured. Recall in Section 3.4.1 that I discussed how one's imagination can lend itself to finding new understandings of who one is (in the context of illness or injury) as well as assist in discovering what may be "realizable" possibilities for the future. The "imagining together" that health care providers and patients could do, especially as part of learning what life is like with a chronic illness or disability, would be one way for health care providers to

enhance the ability of patients to hope. For example, knowing that hope affects what one attends to and how one acts, health care providers may be able to help patients discover (new) ways in which their “bad days” with a chronic illness can become less so and thereby help them to be the “self” they want to be more often. Certainly it seems plausible that if patients with chronic illnesses know a variety of ways to contend with “bad days” and know that their health care providers understand how difficult life with a chronic illness can be, it will be easier for them to sustain their hopes and to take an active role in the care that their illness makes necessary.

Thus, we can see that one additional reason why health care providers may be concerned about whether patients have reasonable or realistic hopes is that what patients hope for can affect their level of involvement in their own care. Indeed, the expectation is that if patients hope to, for example, get better or remain stable, they will be involved in their care and take actions that would help to realize their hopes. While I have already discussed the possible harms that may result if patients hold onto a properly contested hope, this point is slightly different in that its main focus is on finding ways to help patients live their lives as well as possible with their illness or injury. If patients have too little or too much hope for a particular state of affairs, this may be a factor in whether, for example, patients follow treatment programs as closely as they should. What I am saying here should not be interpreted to mean that health care providers should manipulate patients’ hopes as a possible antidote for their non-compliance. Focusing on the issue of compliance/non-compliance by patients often misses the very reasons why a patient may not be able to follow a treatment plan and how ameliorating or addressing some of these

reasons could result in a treatment plan that the patient would be able to and want to follow. In other words, compliance is not always about patients not understanding or contravening what health care providers say, but is often about, for example, a patient's adjustment to living with a chronic illness and her ability to hope that she will be able to manage.

The lesson of this section then is that, in fulfilling their responsibility to foster conditions within which patients can discover and continue to have hope, health care providers must be able to accommodate and appreciate the "fact" that patients are not static - their self-understanding is changing as a result of their experiences with their illness or injury and interactions with others, as is what they hope for.¹⁹ In contesting a patient's hope or her in/actions based on this hope, health care providers should consider how this hope relates to the ability of the patient to cope with her illness or injury (right now and in the future) as well as to the broader context of the patient's process of learning, recovering, and healing. The implicit suggestion here is that a change in focus is required - a change from a reactive stance with respect to patient hope, i.e., one which responds when something has gone wrong with what a patient does or does not hope for, to a proactive stance, i.e., one in which fostering conditions for hope extends, for example, to talking about hope and acting on hope before "problems" exist. I will return to this suggestion and flesh it out in more depth in Chapter Six.

¹⁹ Recall that in Section 3.5.2, where I discussed the opposites of hope (fear and despair), I argued that the ability to hope is a dynamic process that can be intermixed with these other emotions and that patients can experience both hope and fear at the same time. This needs to be taken into account as health care providers consider what patients hope for.

5.3.5: Summary

This discussion has covered a wide range of issues that are all connected to contested hope. I have argued for an alternate terminology that I believe better captures both the variety of ways in which hopes can be challenged and the subjective nature of these judgements. Delving deeper into the judging of hopes brought forth concerns about the power of health care providers to determine what should be hoped for based on (primarily) medical evidence as well as concern about how the context (not only in terms of the clinical situation, but also with respect to the individuals involved) can be factored into judgements about what is appropriate or reasonable to hope for. While I did allow that there may be some situations in which a patient's hope will need to be challenged and changed, it is clear that intervening in a what a patient hopes for should be approached with caution and sensitivity. Finally, a greater appreciation of the person-relative nature of illness or injury, in terms of patients learning more about who they are and/or having to re-define who they are, gave new insight into patient hope. Even when health care providers are contesting a patient's hope, they need to acknowledge that finding and sustaining hope is an interactive and dynamic process. Hope changes what people attend to and how they act; what health care providers say and do with respect to patient hope can affect the process of self-definition and healing. As such, this is also part of what is at stake with false/contested hope and needs to be taken into account in the "calculation" of the harms and benefits of patients holding particular hopes.

5.4 Conclusion

This chapter began with a quote about how social conventions shape and influence what we mean when we state that a particular emotion is reasonable. Through the analysis of hope work and contested hope, a number of assumptions made by health care providers about what hopes (and realities) are legitimate, the grounds upon which hopes can be challenged, and changing a patient's hope were revealed. A privileging of the health care provider's perspective and of medical information and expertise over the situated knowledge of the patient needs to be questioned. While I accept that medical information and experience can inform and be part of discovering what can be hoped for by patients, these should not be the only factors in determining "reasonable" hopes. The patient's values, experiences, and resources all need to carry equal or greater weight when judging hopes, for these are critical features of what makes hope what it is and gives it value in human lives. If these factors are not included and the patient is effectively invisible in discussions about contested hopes or in "hope work," there is a breakdown in the hope care that is being provided for patients and this must be remedied. Thus, the challenge for Chapter Six will be to reflect upon the responsibility of health care providers to foster conditions within which patients can discover and continue to have hope and to consider how health care providers can best meet this responsibility.

Chapter Six

Reflecting on the Responsibility to Foster Conditions for Hope

Hope is seen in the eyes...

Hope is heard in the voice...

Hope is held in the heart.

*Susan Squellati Florence, **Hope is Real***

6.1 Introduction

The time has now come to discuss the normative implications of the work that has been done thus far in this dissertation. I have established what hope is (within the confines of health care) and why it is important, namely that what patients hope for can affect how they live their lives. Further, I have demonstrated that patients are vulnerable with respect to their hope and that health care providers have a key role to play in attending to this emotional attitude. In particular, health care providers have a responsibility to foster conditions within which patients can discover and continue to have hope. Since, in many ways, hope is about relationships and the context within which these relationships are formed and played out, I have argued that feminist care ethics is best suited for fleshing out what this responsibility requires of health care providers. Finally, I have also demonstrated that hopes can sometimes go awry and may need to be changed; however, the relative expertise of health care providers to determine what is “reasonable” to hope for sometimes can, and does need to, be challenged. Thus, with these various aspects of the role of hope in health care in place, the “ethics of hope” must now be addressed.

In the following, I will reflect on the responsibility of health care providers to

foster conditions within which patients can discover and continue to have hope. This involves examining the nature of this responsibility, its (likely) scope and limits, as well as the types of actions that may be required. My analysis will take it as a given that health care providers believe in the value of hope and are committed to helping patients find and continue to have hope and, as such, I will describe ways in which health care providers can work toward meeting their responsibility to foster conditions for patient hope.

The earlier discussion of Tronto's care ethics generally described how the different aspects of care (such as caring about) give rise to certain responsibilities on the part of the care-giver (such as a responsibility to consider what needs others might have). Below, I will expand upon Tronto's treatment of responsibility(ies) with respect to care - as it pertains to the responsibility to foster conditions for hope - and I will argue that valuable insight into how health care providers can best fulfill this responsibility can be generated by thinking of their role as being "backers" or "supporters" of patient hope. I will also show that, while this responsibility does apply in patient and health care provider interactions and that there are things health care providers can do to enhance patient hopes, attending to patient hopes can extend beyond these relationships to include others who make decisions about patient care and about the structure and delivery of health care. As such, I will try to achieve a balance in this chapter between: (1) arguing that health care providers can and should do things now, i.e., make changes to their practices of care within the current health care system to foster conditions for hope; and, (2) arguing that what health care providers can and cannot do to foster conditions for patient hope draws into question the organization, structure, and current focus of health care. I will show that

the issue of patient hope fits well with other critiques that argue that changes to our health care system are required.

Ultimately, I will identify some of the important questions and issues that need to be addressed for a full moral analysis of hope. It would be a mistake for me to presume that I could give a *definitive* account of what the responsibility to foster conditions for patient hope involves since much more research, both in philosophy and psychology for example, is required to better understand the concept of hope and its role in health care.¹

6.2: Nature of the responsibility

Before I move to consider the types of actions that may be part of fulfilling the responsibility to foster conditions within which patients can discover and continue to have hope, it is worth exploring the nature of this responsibility. There are different conceptions of and aspects to our understanding of responsibility. Each carries its own set of assumptions about, for example, praise and blame and the abilities of individuals to meet the demands of the given responsibility. In this section, I will consider some different conceptions of responsibility and defend the one which I believe is the most appropriate and most helpful for understanding the responsibility to foster conditions for hope in health care.

To start this process, it is worth revisiting Tronto's work for she not only informs us about the ethics of care, but demonstrates how various responsibilities accompany and

¹ William Ruddick (1999) offers a similar conclusion in his article, "Hope and Deception." Chapter Seven will discuss three main directions which future projects on the role of hope in health care could take.

arise from giving and receiving care. Based on the four aspects of care she identifies, recall that Tronto argues that the responsibilities of care-givers are to be attentive to the needs of others and to acknowledge these needs when they exist; to determine what can be done to meet needs and to take action accordingly; to provide care that is competent; and, to be aware of how care-receivers respond to the care that is given. Care-receivers have a corresponding responsibility to be responsive in all aspects of care (from expressing needs to responding to the actual care). Thus, we are reminded that the anchor for judging the success of care-giving is in the care-receiver's response and we will see shortly how this factors into what approach health care providers should take to foster conditions for patient hope.² Relatively little more is said by Tronto about what she understands the nature of these responsibilities to be, but she does suggest that, "...we are better served by focusing on a flexible notion of responsibility than we are by continuing to use obligation as the basis for understanding what people should do for each other." (Tronto 1993, 133) She also comments that, "...responsibility is both central and problematic in an ethic of care; responsibility is among the handful of concepts that require constant evaluation." (Tronto 1993, 131)

In these statements by Tronto I find two important points that I want to highlight. The first is that in appealing to a notion of responsibility as flexible, Tronto does not mean to imply that responsibilities can be shirked or overlooked in a way that obligations

² Although I will focus primarily on the responsibilities of health care providers in the following, it is important not to forget that patients do have responsibilities as care-receivers too - not only in terms of responding to care, but also, perhaps, in acknowledging that health care providers are working under certain constraints and may not be able to meet every need nor support every hope.

cannot; instead, Tronto wants to draw upon the idea that responsibilities can do a much better job of taking account of the context of a situation and those involved in it. In other words, talking about responsibilities helps to get us beyond what the “rules” are to who is involved, what the connections between these individuals are, and, accordingly, what care is and how it should be provided.³ Tronto understands care as a practice in which care changes according to who is giving and receiving care; as such, it is not easily described as a set of rules to be followed. Since responsibility can take on and convey different meanings in different contexts, it is better able to make sense of care understood as a practice (see Tronto 1993, 126-133). Second, in stating that responsibility needs to be constantly evaluated as a concept in the ethics of care, Tronto opens the door for investigations such as I am undertaking in this section. What do we mean when we talk about a responsibility to care and to “care about hope”? How should the responsibilities associated with being in a position to care about, take care of, and give care be understood in the context of patient hope? What would be the “best” way to think about this responsibility in order to provide direction to health care providers to foster the conditions for patient hope?

In certain ways, Margaret Walker picks up on the concept of responsibilities at the point where Tronto leaves us with questions. In her book, *Moral Understandings: A Feminist Study in Ethics*, Walker contends that tracing out our responsibilities can reveal the variety of ways in which we are connected with each other and what is (morally)

³ This is reminiscent of the reasons why I shifted to the use of “responsibility” instead of duty, as discussed in Chapter Two.

valued. Indeed, Walker defends an ethics of responsibility and argues that this normative view will help us to determine how each of us should act, with respect to whom, and in what ways.

I propose that it is fruitful to locate morality in *practices of responsibilities* that implement commonly shared understandings about who gets to do what to whom and who is supposed to do what for whom. In making each other accountable to certain people for certain states of affairs, we define the scope and limits of our agency, affirm who in particular we are, show what we care about, and reveal who has standing to judge and blame us. In the ways we assign, accept, or deflect responsibilities, we express our understandings of our own and others' identities, relationships, and values. (Walker 1998, 16)

Since Walker acknowledges that differences in contexts and differences in the individuals present can play a determining role in whether one has responsibilities as well as what these responsibilities are, she retains the flexible notion of responsibility that Tronto wanted for her ethics of care.⁴ As Walker points out, attending to the social practices and shared understandings that “explain” why some responsibilities are accepted and others deflected reveals who and what is considered worth devoting one’s time to and what is of moral value. Further, since our responsibilities arise from and are based within our social practices and can change as these responsibilities are negotiated and examined (formally or informally), a focus on obligations and duties will tend to miss these aspects of moral life. As Walker puts it: “[An ethics of] responsibility invites detailed and situated descriptions of the expectations and negotiations surrounding assignments of responsibility.” (Walker

⁴ Walker does state that she hopes her ethics of responsibility captures what is considered important in feminist versions of the ethics of care (see Walker 1998, 107).

1998, 16)

What can we learn from applying Walker's ethics of responsibility to the responsibility of health care providers to foster conditions for patient hope? First, it is clear that how a responsibility is understood can make a difference to how it is fulfilled. As I demonstrated in Chapter Two, health care providers have often been told that it is their duty to promote, maintain, or instill hope in patients. I argued there that this "duty" suggests an approach to patient hope that is problematic, since this approach tends to ignore who the patient is and her perspective in both discovering and evaluating what can be hoped for. In making health care providers responsible instead for the fostering of conditions for patient hope, I argued that this responsibility is more suited to the role that health care providers can and should play in what patients hope for. Second, Walker points out that moral choices are made not only in deciding what actions to take (or not to take) based on one's responsibilities, but also in accepting and recognizing one's responsibilities and in how one chooses to understand what this responsibility asks of oneself. Thus, there are moral implications attached to how I choose to describe the responsibility of health care providers to foster conditions for patient hope. I have already made and defended one choice about how this responsibility will be interpreted and guided, namely that it is situated within a feminist ethics of care framework.

The second choice I make here to flesh out the nature of this responsibility is to draw upon an analysis of *taking responsibility* by Claudia Card. In her discussion of responsibility and moral luck, Card offers the following comments on taking responsibility:

...taking responsibility for something does not require that we identify ourselves as its author, originator, or cause. We may identify ourselves, rather, as backers, supporters, maintainers, developers...In so doing, we become committed to the value of that for which we take responsibility – not necessarily to its success (although that is a possible value), but to making something of it...(Card 1996, 145)⁵

This conception of responsibility is clearly different, for example, from the “managerial” sense of responsibility that Card also describes. The managerial sense of responsibility involves “undertaking to size up and organize possibilities comprehensively, deciding which should be realized and how..” (Card 1996, 28) I believe Card’s description of responsibility, in terms of being committed to the value of something and acting as a backer or supporter for it, is consistent with a feminist care ethics approach and helps to encourage our thinking about how the responsibility of health care providers can be fulfilled along more productive lines (as I will explain below) than the managerial sense. Until now, I have been concerned to ensure that patients have a primary role in determining and sustaining their hopes, but have acknowledged that patients do rely on and require assistance from health care providers in this process. Part of my difficulty in clarifying what health care providers should do with respect to patient hope has been in finding the right words to express how they can care about patients and what they hope for without becoming the primary actors. Card’s description of taking responsibility has helped me to find the right words. Patients, as care-receivers, should be understood as the

⁵ Card relies on Joyce Trebilcot to inform this part of her analysis of taking responsibility. I have chosen to utilize Card’s presentation of these ideas, as I find that what Card says better fits with the project I undertake here. (See also Trebilcot 1994, 98-99.)

initiators or originators of hope, or of the need to attend to patient hopes, and they can stimulate health care providers, as care-givers, to back or support the value of this need.

The metaphor of being a supporter or backer of something can be extended to think creatively about the various ways in which the responsibility to foster conditions for patient hope can be met. For example, a supporter of X - X being something that is considered worthy or of moral value - would likely be expected to devote time and energy, even money, to the creation or maintenance of X, to assist in identifying and working toward conditions within which X will be more likely be able to flourish, and to provide advice or special knowledge that might assist the “leaders” or “main players” in furthering X and sustaining interest in it. Thus, rather than always thinking of health care providers as needing to take charge and act “on” the patient, we can instead view health care providers as supporters of patient hope. This means they would help patients find hope(s) - both through their interactions with individual patients and through working toward changes in how health care is structured and delivered that will positively affect the ability of patients to hope and/or foster an environment within which the value of hope is recognized.

There is another sense in which supporters or backers are also involved in creating or maintaining X - namely, supporters, in giving advice or assisting in creating conditions favorable to X, have a critical role both in evaluating those conditions and advice and in helping to ensure that the actions taken by the main players are suitable/acceptable. If health care providers encourage a patient to hope for a particular state of affairs, then they should bear some responsibility for the results that follow from the patient having that

hope. And, it would seem that the severity of the consequences or degree of harm that may result from holding and acting on a particular hope can affect the degree to which health care providers are considered responsible for the patient and what she hopes for. The difficulty however is in determining to what extent or to what degree the health care provider is to be held responsible for the emotions and actions of another, the patient, and to what extent those emotions and actions are “out of the hands” of the health care provider.⁶

Some further comments from Card about taking responsibility are helpful:

When are we in a position to back something, to stand behind it? Being in a position to stand behind something requires being able to carry out tasks that constitute backing it, making it good. Except for my ability to defend a thing's existing or realized values, I am unable to stand behind something when I cannot affect it and when I can neither repair nor compensate for the damage it does. (Card 1996, 146-147)

Earlier, I demonstrated that health care providers can affect patient hope and can help repair and/or avoid the harm that may result from patients hoping for a certain state of affairs and acting on this hope. For example, in Chapter Five I suggested that it is possible for health care providers to mitigate the “damage” that may come to an individual or others as a result of a particular hope by helping to create safeguards. In Kay's situation, the safeguards for her to be able to continue to work included permission for her

⁶ Alternatively, it is possible that a supporter may choose to withdraw from a situation, if she believes that the main players are going too far astray and she cannot be a party to this or cannot help to bring them back. As I have argued, health care providers can withdraw their support for particular patient hopes, but this “option to withdraw” should not be interpreted to mean that health care providers should necessarily withdraw completely from patients whose hopes they do not support.

supervisor and head physicians to talk to her psychiatrist and to relieve Kay of her hospital privileges if necessary. If Kay's ability to work is affected by her manic-depression, these safeguards will help to minimize the harm that may result both to Kay and to her patients. Thus, even if health care providers do not change or redirect what a patient hopes for, health care providers can still play a role in caring for the patient with respect to what she hopes for. In addition, as supporters or backers for patient hopes, health care providers may be able to help give weight to the caring activities that foster conditions for hope and assist in ensuring that the time, money, and/or personnel needed for these activities are recognized as valuable, for example, by hospital administrators. Health care providers can thereby support patient hope by playing an advocacy role in drawing attention to the value of fostering conditions for hope in health care and to the material conditions this requires.

At this point, a word of caution as to how portraying health care providers as supporters or backers for patient hope should *not* be understood - that is, health care providers should not be understood to be "cheerleaders" for every and all patient hopes.

Consider the following comments:

[Question:] Would you say hope helps organize the way in which you relate to patients? [Oncologist:] I try to make patients feel better after they have seen me. I'll always focus on the positive. [If t]hey look good, I'll tell them they look good. If their weight has gone up an ounce, I'll focus that their weight has gone up an ounce. Whatever it is. Because in part I'm their cheerleader. *I've got to be their cheerleader.* (Good 1990, 71; author's emphasis)

Physio was hell. Iolanda's [the physiotherapist's] cheerleader act was wearing thin as I struggled through the easiest of exercises. Don't give up. Don't give up. I couldn't handle sucking ice cubes. I could hardly swallow. I

was racked by coughing spasms, bringing up disgusting, thick white phlegm. All day I coughed and choked until my throat was raw and my lungs aching. You can do it, Bonnie. (Klein 1997, 66-67)

While it may be true that pointing out the positive aspects of patients' situations (such as the increase in weight) will help patients to maintain their hope, there is a danger that "being positive" can be carried too far in, at least, two respects. First, acting as "cheerleader" can be carried too far in terms of suppressing the honest expression of emotions by patients. For example, the patient may feel that she always has to "put on a good face" for the health care provider and/or has to respond well to the cheerleading routine, such as by pretending to be cheered up and "happily" continuing with her treatment when she really wants to stop treatment or really needs to discuss what the value of continued treatment is along with her fear and anger about what is going to happen. Second, if health care providers see themselves primarily as cheerleaders, this may prevent them from critically assessing just what it is they are cheering for. While supporting patient hope is important, this is not to say that every hope is legitimate or is for a reasonable state of affairs. Health care providers need to be careful about what they are being positive about - is it reasonable to be positive that you, the health care provider, can help a patient completely recover? Or is it more reasonable to be positive that you can help the patient deal with this illness or injury?

Depending on the context, what health care providers can cheer for may change and, as Bonnie's reaction to her physiotherapist's cheerleading demonstrates, it may be worth taking a break from playing this role all the time with patients. Accordingly, I

understand being a supporter or backer of patient hope as an active, ongoing responsibility that demands health care providers not only focus on patients and what they hope for, but also focus on or critically evaluate what their own role in patient hope is as a care-giver. For example, as I discussed in Chapter Five, health care providers will sometimes need to “correct” what a patients hopes for, but they need to be cautious about assuming that a contested hope must be changed. It is also the case that being a supporter for patient hope does not mean that health care providers can never challenge what a patient hopes for; indeed, as I discussed earlier, health care providers can recognize the value of patients having hope without having to support or accept each state of affairs that patients hope for.

This theoretical discussion of the nature of responsibility, as it pertains to the responsibility of health care providers to foster conditions for patient hope, has revealed that there are different ways of understanding this responsibility. Overall, the best interpretation of this responsibility to foster conditions for patient hope is to understand health care providers as backers or supporters for patient hope; this interpretation coincides with much of the analysis undertaken in this project. As supporters of patient hope, health care providers can both identify and respond to the hope needs of patients without becoming the ones who necessarily determine what patients hope for. Finally, it is becoming more clear that part of fulfilling this responsibility well depends on health care providers acknowledging that they are active participants in these “conditions for hope;” as such, health care providers need to evaluate what they say and do as these actions relate to and affect what patients hope for.

6.3: Fulfilling the responsibility - Care-giving by health care providers

Now that the nature of the responsibility to foster conditions within which patients can discover and continue to have hope has been fleshed out more fully, I can consider what “fostering conditions” means from the health care provider’s perspective as a care-giver, in terms of being a support/backer of patient hope. Recall Tronto’s description of what care-giving is: it involves the direct meeting of patients’ (hope) needs and there is an expectation that this care will be given competently. This description of care-giving implies that: (1) possible actions and directions for meeting patients’ hope needs can be identified and carried out by health care providers; and, (2) these actions and directions can be evaluated both in terms of how well health care providers perform them and in terms of how well patients’ hope needs are met.

Accordingly, the task for this section - which is broken down into three parts - will be to lay out possible ways for health care providers to work towards fulfilling their responsibility to foster conditions for patient hope and to critically assess the suggested/available choices. First, I will investigate some of the directions and actions commonly recommended to health care providers for enhancing patient hope - as one route that health care providers could take for fostering conditions for hope. We will see that the “recommended” directions/strategies are primarily focused on patient-health care provider interactions and that there are two general categories of suggested actions; one is, as may be expected, to improve or increase communication with the patient, and the second is to utilize new strategies designed specifically to enhance hope. I will identify important gaps in or problems with these recommended strategies and, as such, will argue

that more research needs to be done in order to determine what strategies will work best for particular patients and in different clinical contexts. In addition, the role of health care providers' own hopes in relation to their ability to fulfill the responsibility to foster conditions for patient hope will be discussed. Finally, I will broaden the discussion to include considerations of the health care context, identifying some practical changes that would help to foster conditions for patient hope.

6.3.1: What the "Studies" Say and Don't Say

In Farran, Herth, and Popovich's book, *Hope and Hopelessness: Critical Clinical Constructs*, the authors devote an entire chapter to suggesting possible strategies for use in the clinical setting that could influence patient hope. These strategies are grouped together according to the different aspects of hope they have identified, i.e., hope's experiential, relational, spiritual, and cognitive aspects. Moreover, the authors recognize that an individual's experiences and present illness or injury, her connections with others, and her beliefs and goals can affect what is hoped for. Their recognition of these aspects of hope is similar to my analysis of hope and it therefore seems reasonable to employ their breakdown of the suggested strategies. Further, the authors contend that being able to address or keep in mind these different aspects of hope may assist in finding what strategies will work best for enhancing a particular patient's hope and thereby acknowledge the subjective nature of this emotional attitude. Some of the strategies

suggested by Farran, Herth, and Popovich include:⁷

Experiential - patients may need help in identifying areas of hope in life and to recognize that hopelessness and hope can be fluid and transient. Health care providers may need to help patients acknowledge that changes in health, loss of emotional/physical energy, etc. can affect their ability to hope and exhibit confidence in the patients' abilities to overcome these "threats" as well as take steps to minimize them.

Relational - to encourage a sense of connectedness and care (that can help foster hope), health care providers can actively listen to patients and be present/available for them, help patients to establish support systems with family, friends, groups, encourage patients to find something or someone to care about (family, pets etc.) and positively reinforce hopes that are expressed.

Spiritual - fostering hope may stem from encouraging patients to record their feelings and experiences or helping patients to find joy in the "small" or "day-to-day" features of life or finding ways to express and explore their values and beliefs.

Cognitive - helping patients to set attainable goals or to break a goal down into more manageable/achievable steps, clarifying information related to the illness or injury, assisting in identifying and/or accessing internal and external resources, and trying to give patients some sense of control over what has happened or is happening may all affect patient hope.

This is only a sample of the various strategies that are described by Farran, Herth and Popovich; however, I do believe the sample reflects the general tenor of all the given strategies. Interestingly, a majority of the strategies the authors identify tend to be things that should already be part of good health care, such as actively listening to patients, being available for them, and explaining/clarifying information about illness or injury. These

⁷ I will not utilize the following headings for the different aspects of hope that Farran, Herth, and Popovich identify in the rest of this section, but I will use them here to help separate the various types of interventions the authors suggest. I rely on p. 108 - 117 in Farran, Herth, and Popovich (1995) for this overview. The authors do point out that, "Although these suggested interventions/strategies have been proposed clinically, they still need to be tested and validated in the wide variety of clinical populations." (Farran, Herth, and Popovich 1995, 108). They thereby acknowledge that different clinical contexts may affect what strategies will work best. Very similar types of interventions are also described by Dufault and Martocchio (1985).

strategies are recommended primarily when patients have lost or lack hope.⁸ In a sense then, these types of strategies suggest that improving or attending more closely to the activities that are generally considered part of caring for patients - but with a focus on hope - will assist patients in finding hope. Yet, it also seems that if these strategies were utilized in all, or even most, interactions with patients, health care providers would be better able to support patient hope overall by helping to create an environment within which hope is attended to on a regular basis and not only when “problems” with patient hope occur.

Employing these strategies more often or on a regular basis would help health care providers to respond to the often-changing nature of patient hope and to be able to determine, for example, whether “being down” is part of the recovery process for a particular patient and/or whether changes should be made to the care that the patient receives, based on what she hopes for. In other words, given that hope can fluctuate and change from day-to-day as I argued in Chapter Five, it seems that following what a patient hopes for during her treatment or recovery may be just as important as following the patient’s blood counts or improvement in muscle strength. Knowing what a patient hopes for, beyond just whether she is able to hope, will give important insight into how this patient is dealing with her illness or injury and how health care providers can best respond with the care that they give to this patient. As Arthur Kleinman explains:

⁸ The chapter on strategies for enhancing patient hope comes after a chapter describing measurement tools for assessing a patient’s hope and/or hopelessness in Farran, Herth, and Popovich’s book.

The kinds of changes that matter in the care of the chronically ill are usually not dramatic ones: they tend to be small changes in the perception of symptoms and in the tolerance of suffering. The space between a manageable distress and a defeating despair is often narrow...What is more, care with the same patient may be successful one week, unsuccessful the next...Care is a constant struggle to experiment and persevere—like the illness experience itself. (Kleinman 1988, 249)

In addition, part of what the different strategies described by Farran, Herth, and Popovich point out is that sometimes there isn't something special or different that needs to be done to foster conditions for patient hope. Often just treating patients as persons, conveying a sense of caring, understanding, and honesty, can be enough to create an atmosphere within which patients can find and discover hope. This point is reinforced by the results of a study by Gina Wong-Wylie and Ronna Jevne on interactions between physicians and HIV-seropositive individuals. Wong-Wylie and Jevne found that the interpersonal relationship established between patients and physicians had much to do with whether the patients perceived their interactions with their physicians as "hope-full" or "hope-less." Five critical aspects of these relationships were identified that made a difference to enhancing or inhibiting patient hope: a) whether the patient was treated as person and not as a case; b) whether the patient could talk openly or "connect" with the physician; c) whether the attitude taken by the physician in explaining information to the patient was descriptive or prescriptive; d) whether the physician was welcoming or dismissing of questions, etc.; and, e) whether the physician made an effort to inform the patient of test results, etc. (Wong-Wylie and Jevne 1997) In effect, this study reinforces my earlier arguments that what patients hope for is affected by the relationships they have

with others and, in particular, with their health care providers (see Chapter Four). The underlying message of this study and the suggested strategies is that a focus on improved communication - because it establishes better (more open, honest) relationships with patients - is one way for health care providers to work towards fostering conditions for patient hope.

Yet, some of the strategies mentioned by Farran, Herth, and Popovich do not fall under the “typical” forms of care given by health care providers. For example, two suggestions made above are to have patients write down their feelings or to help them find joy in the “small” things in life. Other related strategies for enhancing hope in patients have been suggested by Ronna Jevne. These strategies include:

Hope stories: You may tell hope stories or the patient may tell them. You might ask patients to generate one a day... You can put them on audiotape or videotape...

Hope rituals: Identify the rituals that the patient performs each day or week. How can these be used therapeutically? ...Hope rituals may relate to belief or behaviour. One young woman who suffered depression after the loss of her mother chose to do a simple little dance each evening as part of her bedtime ritual. She felt she wanted to symbolize that she would continue to celebrate life despite her pain...

Hope models: Everyone has a real person, a storybook character or a television personality, who can act as a hope model, who often has attributes that the [patient] needs or admires. By aspiring to the hope model, patients may take on its attributes when their own hope or strength fails... (Jevne 1993, 127-128)

These strategies encourage both patients and health care providers to think about what to hope for and to act on this hope, often in very concrete ways, such as by recording a hope story or developing a ritual. As these strategies indicate, talking to a patient about hope

may not be enough in some cases to support what this patient hopes for or to help her find something to hope for. Thus, fostering conditions for patient hope may sometimes require health care providers to be creative (or to think “imaginatively”) and/or to employ the options suggested by Jevne for helping patients to find, explore, and sustain their hope.

One of the things that Jevne also makes clear in her writings on hope is that hope doesn't have to be for the “big” things in life, but can be focused instead on something small or achievable for that day or even for the next hour. In other words, in fostering conditions for hope, health care providers should not fall into the trap of thinking that they have to make life turn out well for every patient far into the future or that when a patient asks about possibilities for hope that this means the patient is asking about what will happen over the next five years. It may be that focusing on the near future or immediate future is all that a patient wants to know about and wants to be able to hope on this basis. The hope ritual, for example, serves as a reminder that there is something to hope for each day and that actions taken to support hope do not have to be “grand” or “big” things. As Patty Duke, a woman with manic-depressive illness, explains,

...sometimes it is the simplest, seemingly most inane, most practical stuff that matters the most to someone. We can explore all the esoteric concepts and philosophize all we want to, but sometimes somebody just wants to know, “Is it a yellow pill or a green pill? Do you take it with water or milk? Is it going to make you throw up?” (Duke 1992, 243)

If health care providers mistake their responsibility to foster conditions for patient hope to imply that they must be able to make the future “bright” for each patient, then the smaller ways in which they can reassure and help patients to cope with their illness or injury and

potentially find/sustain hope may be lost, as the examples given by Duke remind us.

Thus far then, we have seen that working towards conditions within which patients can discover and continue to have hope can take two different, yet complementary, directions (as suggested by the hope literature): the first is to focus generally on the interpersonal aspects of interactions with patients which will likely have a positive effect on patients' ability to hope; the second is to employ strategies specifically designed to foster hope(s). As I move into my critique of these suggested strategies, it is important to establish that I do not deny that the above-described directions and actions offered will often be able to enhance patient hope. However, these actions and directions are insufficient for fulfilling the responsibility to foster conditions for hope, i.e., there are other changes or new practices of care that are required as well.

First, I want to draw attention to a possible, problematic interpretation of these strategies: namely, that health care providers only need to use these techniques when a patient doesn't have hope or is finding it difficult to sustain hope. Fostering conditions for hope should extend beyond the "problem" cases; opening discussion about hope or being aware of what "all" patients hope for should be a valued part of caring for patients, as I suggested above with the general strategies for enhancing hope in patients. If hope makes a difference to how patients live their lives, this implies that attending to what patients hope for should be a part of the care they receive throughout their diagnosis, recovery, treatment, and/or adjustment to a life changed by illness or injury. For example, even if they are able to hope at the current time, patients may benefit from being made aware of the hope-specific strategies, since this indicates that their health care providers are

interested in the emotional or psychosocial aspects of being ill or injured and are willing to help patients find ways to cope and to heal.

Second, even though I do believe in the value of honest and open communication with patients, there is a danger in taking, at face value, the claims that improved communication will enhance patient hope, if these forms of communication are not shaped by considerations of how to best meet patients' hope needs. By drawing attention primarily to things like communication as a strategy for enhancing hope, this approach suggests that all health care providers have to do is care "better" for patients, i.e., by devoting more time to the practices of care that are already undertaken or believed should be undertaken. As I have shown in this dissertation, there are problems with some of the current practices of care in terms of adequately meeting patients' hope needs. Recall the problems I identified both with the "hope work" observed by Perakyla and the assumptions typically made about the legitimate grounds upon which to contest a patient's hope. These problems suggest that simply working harder at giving care to patients (by talking more to them) may not enhance patient hope and/or may even make things worse because, for example, the health care provider's view on what is a "realistic" hope may be more forcefully argued with patients. This implies that there is a need to evaluate current practices of care before it is suggested that these are the best way to foster conditions for patient hope. The choices made about how to improve discussions with patients about hope or to bring attention to patient hope must be informed about hope and appreciate, for example, the patient's vulnerabilities with respect to what she hopes for.

A related problem with the described strategies having their focus on "talking"

with patients about hope is that this “talk” emphasis overlooks other important ways through which care can be conveyed to patients, for example, by touch and body language. It is important to remember that care-receivers respond not only to *what* care is given, but also to *how* the care is given. As Ronna Jevne points out, “Caring ...may be conveyed by tone of voice, touch, eye contact as much as words.” (Jevne 1993, 126) In order to illustrate this point, reconsider the discussions between Darcy and her oncologist and family physician (I analyzed this case in Section 4.2):

The day before my release, Dr. Barnes [the oncologist] came in early to see me because he had to leave town for a few days. He sat on my bed, only the second time he did so, and after he examined me we spoke about the chemotherapy. I would receive treatment in his office, located in the hospital complex...We spoke some more about chemo, which I felt was pretty tolerable, but to my surprise he reacted oddly. He stood up and said, “If you think this is manageable, wait until you have a bone marrow transplant!” I looked questioningly at him. “You’ll be so full of drugs—really sick. You won’t thank me then.” (I had thanked him earlier for saving my life.) He abruptly left.

I sat in my bed confused, scared, and hurt. What had I said? Why a transplant? Had I crossed a line with him? Dr. Douglas [her family doctor] came in to find me in this emotional muddle. “What’s the matter, Darcy?” he asked and quickly came over and sat by me. I told him what had passed between Dr. Barnes and me; after 20 minutes of hand-holding and explaining why I probably would not need a bone marrow transplant—I was responding so well to this chemo—I cheered up. (Lyn 1994, 27)

It is interesting to note how the body language of the oncologist and the family physician probably added to Darcy’s interpretation of what was said. Darcy comments that the oncologist sat on her bed - “the second time he did so” - which conveyed to Darcy a sense of intimacy and care. But then the oncologist delivers his comments about the bone

marrow transplant standing up; his move to the upright position most likely added to Darcy's fear and sense of vulnerability. Standing up also made it easier for the oncologist to leave quickly after making his "pronouncement," destroying the earlier atmosphere of care that had been created. The oncologist's rush to leave the room implied to Darcy that her reaction to what he said about the possibility of a bone marrow transplant is not worth his time.⁹ In contrast, Darcy's family physician comes in and quickly sits by her, holding her hands as a form of comfort (if I can read her comments literally - Darcy does mention at another point how her family doctor massaged her feet for her). The family physician's close contact with Darcy helps to convey the message that he cares about her and wants to hear what is wrong. Although words were said in both cases, the body language of the two physicians clearly played a role in how Darcy reacted; the fact that she knows how many times the oncologist sat on her bed illustrates the significance of this action to Darcy.

The most important problem with these strategies however is that they fail to address how, even if health care providers support what a patient hopes for, they may destroy this hope by failing to appreciate the effects of what they say and do on patient hope. Health care providers need to recognize how vulnerable patients can be with respect to their hopes. For example, the joke the health care provider makes about a patient's hope may be taken to heart by the patient and her hope shattered. Health care providers cannot focus "just" on specific strategies or tactics for improving patient hopes. There

⁹ Recall that feeling as if one has been dismissed by one's physician is one of the features of patient-physician relationships that can inhibit hope as reported in the study by Wong-Wylie and Jevne (1997) cited above.

must be a recognition that “how” patient hopes are or are not taken into account in the everyday practices of care matters as does who the patient is. The timing of discussions with patients, who should be involved, etc. are all part of the *how* to foster conditions for hope and *how* to give hope care that meets each patient’s needs. Thus, the ideal of competent hope care would be for health care providers to attend to hope in all of the different forms of care that they give to patients. Of course, there will be practical limits, such as time and resources, on reaching this ideal; I will discuss some of these limits below. But, knowing what the ideal is or could be can assist in identifying changes that both can be made (now) by health care providers and to health care generally in order to work towards this ideal.

6.3.2: Health Care Providers and Hope

One aspect to consider with respect to the responsibility to foster conditions for patient hope is what health care providers themselves hope for and how this could affect their ability to fulfill this responsibility. Thus far, I have only alluded to health care provider attitudes and beliefs as a confounding factor in situations where health care providers contest patient hope. But what of health care providers’ own hopes? What are reasonable or appropriate hopes for health care providers and how do these hopes relate to their responsibility to foster conditions for patient hope? Should the fostering of conditions for hope include fostering conditions within which health care providers can find and sustain their own hopes; will these conditions be the same? Taking patient hope seriously entails taking the hope of health care providers seriously as well. My goal here is

to outline a series of issues that relate to determining what the relationship is between health care providers' own hopes and the responsibility to foster conditions for patient hope, especially if we conceive their role as one of being backers and supporters of patient hope.

If hope can affect how one lives one's life, it seems that what health care providers hope for, especially as this pertains to their professional activities, will affect how well they are able to care for their patients and what these patients hope for. Being "good" care-givers entails that health care providers should be aware of how their own perspective and their own needs can shape how the needs of care-receivers, patients, are identified and responded to. The background assumption in both this project and in much of the hope literature is that what health care providers hope for is "fine" - either in the sense that it does not affect how health care providers interact with patients or in the sense that their own hopes do not need to be evaluated nor require support. But as Ronna Jevne observes:

The life of a health care professional can be taxing. Idealism wears thin under the stress of patients' demands, the developments of technology, the policies of governments and institutions, the long-term exposure to suffering and the mixed blessing of aging. Like the patients you [health care providers] will serve, your health and well-being will be influenced by your vision of the future and of medicine. (Jevne 1993, 129)

In the world of suffering, those of us called "caregivers" grapple to find a rightful place for hope in our "professional" frameworks. We wrestle with roles and policies and procedures as they come in conflict with our sense of what is truly needed. (Jevne 1994, 111)

Jevne suggests that the role of hope in the health care provider's professional life can be difficult to determine. On the one hand, there is a desire to sustain hopes about the future and about the positive healing/helping role of medicine and to utilize these hopes in providing care for patients; but, on the other hand, there are the competing demands of hospital and government policies and procedures in addition to the demand for health care providers to help alleviate and deal with the emotional and physical suffering of patients. Finding the balance between these different demands, such that burn-out for example, can be avoided may be extremely difficult for health care providers. As John Bruhn (1984) comments, "The caregiver...must come to grips with his own limitations to give hope and to heal." (217)

Although Bruhn does not further expand on what these limitations are, various limitations can be identified that may be relevant for health care providers in terms of their ability to "give hope and to heal" as well as to sustain their own hopes. These limitations include: the limits of available medical treatments; the limits of individual care-giver's expertise, time, emotional and physical capacities; the limits set by policies, procedures, and cutbacks; and the limits of being able to control another person's emotions. Health care providers frequently have to make choices about who will receive what care within these limits and may sometimes not be able to balance out the different demands created by these limits. When health care providers are under severe stress, it may mean that attention to the conditions for hope or to an individual patient's hope may (have to) be sacrificed in order to meet other pressing needs. Depending on the situation, this choice may sometimes be morally acceptable and other times not. For example, consider a

situation in which a patient hopes to go to her son's piano recital the following day; the physician knows that her blood counts are too low for her to safely leave the hospital and yet is unable to convey this information to the patient in time for her to arrange for someone to tape record her son's performance (and this was a suitable alternative for her). Should the health care provider be held responsible in whole, in part, or at all for the emotional hurt this patient experiences?¹⁰ Being placed in situations like this will certainly affect the health care provider's ability to hope, for example, that she can help patients with their illness or injury or that she can make a positive difference in patients' lives. If health care providers need hopes like these in order to foster conditions for patient hope (and this is a relationship that will need to be worked out), then attending to what limits are in place on what health care providers can do and how they can negotiate these limits becomes an important feature of this responsibility.¹¹ Cutbacks to a day-program at a mental hospital, for example, may mean that health care providers are less able to assist patients with the transition from the hospital to the community. These health care providers may become discouraged about what help (and hope) they can offer to their patients, especially to those who could live in the community if the right supports were in

¹⁰ Filling out the "accountability" aspects of this responsibility as to when health care providers should be morally blamed or praised will be an important future project. In addition, working with and within the identified limits should be informed by accounts of relational justice such as I discussed in Section 4.5.

¹¹ Attending to these limits is also a responsibility of care-receivers in the sense that if patients appreciate the constraints that health care providers are under, they (patients) could, for example, identify which of their caring needs is most important and/or advocate for changes to health care such that health care providers are given more support (time, etc.) and will thereby be better able to meet patients' needs.

place.

Understanding and attending to how health care providers deal with these

“limitations” is important for a further reason which Tronto identifies:

Care-givers often must subordinate their own caring needs to those of the person, thing or group to which they are providing care; the nurse may not have had a lunch break, but she still needs to take care of this patient...As a result, care-givers are often enraged about their own unmet needs. If they are unable to recognize this rage, care-givers are likely to vent their anger on those for whom they care. Perhaps some rage is appropriate, but when it subverts the process of care itself, then it poses a serious moral problem. (Tronto 1993, 144)

As Tronto suggests, it is important to consider the role of “limits” on care that should/should not be given as this pertains to the possible exploitation of health care providers (recall the discussion of exploitation in Section 4.5) . In trying to determine what the responsibility to foster conditions for hope asks of health care providers, it is worth noting (perhaps even stressing) that there will be practical limits on what health care providers can do and I have tried to capture, or at least suggest, that reality in the wording of the responsibility. Talking about the responsibility to *foster* conditions for hope as opposed to, for example, *creating* conditions for hope suggests that health care providers will not be able to “do everything” for patient hope nor are they expected to. Fulfilling this responsibility would not require health care providers to ameliorate social injustices etc. that extend beyond health care “proper” or to provide a full support system for patients when they have no family.¹²

¹² Of course, some health care providers may extend their advocacy role for patients to include challenging social policies and norms that affect the health of citizens.

What needs to be recognized here is that attention, understanding, responsiveness, promoting the other's good, and so on are all activities that admit of degree. Furthermore, pulling out all the stops for every individual one comes across is not only not humanly possible but may also be inappropriate for many individuals or in many situations. (Dillon 1992, 76)

The main difficulty with trying to describe what is (properly) involved in fostering conditions for hope is determining what "degree" of action is appropriate and what choices should be made or priorities given to the various measures health care providers could take to foster conditions for hope (their own hopes and those of patients). Working out an answer to these concerns will further involve considering the role of others, such as insurance companies, governments, hospital boards, etc., as their decisions about what programs will be funded, how many staff positions will be cut/added, all affect how well (and whether) health care providers are able to foster conditions for patient hope. (I take this up further in Section 6.4.)

Another issue to take into account as part of fostering of conditions for hope is whether the need for health care providers to have hope may change or shift depending on the clinical context.

How much hope or possibility-supplementation is needed varies somewhat with the disease and medical specialty, as well as the patient. Oncologists need more hope than internists, and internists need more hope when treating a patient with multi-drug resistant tuberculosis than a patient with acute bronchitis. (Ruddick 1999, 351)

Ruddick's contention is that the clinical context can make a difference to the role that

My point here is that fostering conditions for hope does not necessarily require this of health care providers.

hopes play in the professional life of health care providers. In other words, due to increased uncertainty and/or due to the variable stakes (death versus permanent disability versus treatable acute disease) in different clinical contexts, some health care providers may need more support (or find it more difficult) to find or sustain, for example, the hope that a particular treatment will work. But does this need to be the primary hope a health care provider has? One of the concerns I have about focusing on or linking the hopes of both patients and health care providers to the possibility of a treatment working is that this tends to (over)emphasize, again, the hope for cure. If health care providers base their ability to do their jobs well primarily or solely on their ability to cure their patients, this will have an impact on how they understand the fostering of conditions for hope, i.e., the focus will be on new treatments and research. The danger then is obvious: health care providers who believe the hope for cure is the most legitimate hope may hold out the hope for cure to their patients or encourage their patients to continue treatments when the “real” benefits of these treatments for the patients are in doubt or, further, other hope needs of these patients will not be met nor recognized. What I want to draw attention to here, as I did in Section 4.5, is that how health care providers understand their role and the goals of medicine can make a difference to what they hope for and this may in turn affect what hopes they may try to convey to patients.

The upshot of this brief look at health care providers and hope, in the context of their responsibility to foster conditions within which patients can discover and continue to have hope, is that in focusing on and talking about patient hope, we should be careful not to overlook health care providers themselves. What health care providers hope for as well

as what they believe about the value and/or nature of hope will affect how they understand and try to meet this responsibility.

6.3.3: Broader Considerations - What about the Context?

I have said much about the importance of attending to the context within which patients discover and continue to have hope, especially with respect to the judging of hopes. In this section, I will address some of the more practical or concrete aspects of the health care context that can positively or negatively affect patient hopes. As such, I will move from concentrating solely on things that health care providers can do to enhance patient hopes and begin to consider in more depth the constraints within which health care providers must attempt to foster conditions for hope. For example, even “just” employing the aforementioned strategies for enhancing patient hope on a regular basis will entail changes in practices of care. Being able to discuss hope rituals with patients and even being available to talk “more” with patients means that time will have to be found for these activities or the emphasis in these practices of care shifted to accommodate hope. How will this happen? What are some of the important features in how health care is organized and delivered that will need to be addressed as part of fostering conditions for patient hope?

As a first step in developing a better understanding of how the actual context of care can impact on being able to foster conditions for hope, consider Arthur Frank’s experiences:

During my chemotherapy I had to spend three-day periods as an inpatient, receiving continuous drugs. In the three weeks or so between treatments I was examined weekly in the day-care part of the cancer center. Day care is a large room filled with easy chairs where patients sit while they are given briefer intravenous chemotherapy than mine. There are also beds, closely spaced with curtains between. Everyone can see everyone else and hear most of what is being said. Hospitals, however, depend on a myth of privacy. As soon as a curtain is pulled, that space is defined as private, and the patient is expected to answer all questions, no matter how intimate. The first time we went to day care, a young nurse interviewed Cathie and me to assess our "psychosocial" needs. In the middle of this medical bus station she began asking some reasonable questions. Were we experiencing difficulties at work because of my illness? Were we having any problems with our families? Were we getting support from them? These questions were precisely what a caregiver should ask. The problem was where they were being asked.

Our response to most of these questions was to lie. Without even looking at each other, we both understood that whatever problems we were having, we were not going to talk about them there. Why?...we had to assess the kind of support we thought we could get in that setting from that nurse. Nothing she did convinced us that what she could offer was equal to what we would risk by telling her the truth.

Admitting that you have problems makes you vulnerable, but it is also the only way to get help. Throughout my illness Cathie and I constantly weighed our need for help against the risk involved in making ourselves vulnerable. If we did not feel that help was forthcoming, we suppressed our need for expression. If we had expressed our problems and emotions in that very public setting, we would have been extremely vulnerable. If we had then received anything less than total support, it would have been devastating. The nurse showed no awareness or appreciation of how much her questions required us to risk...(Frank 1991, 68-69)

Extending my earlier analysis of vulnerability and patient hope, this example vividly

portrays the difficult situation that patients may find themselves in when deciding how much to share and how much support or help will be received. Is it worth the risk? Being vulnerable with respect to hope implies that we cannot simply say patients and health care providers need to talk about hope – there also needs to be some sense that it is “safe” for patients to talk about their hopes and fears and to express their anger and frustration.¹³

Here I don’t mean “safe” in the sense that health care providers can never challenge what is hoped for by patients and/or the actions taken on this basis, but “safe” in that there will be a genuine effort by health care providers to understand the importance to that patient of what is hoped for and how this hope fits into her life.¹⁴ Frank clearly demonstrates how vital privacy is to feeling “safe” to talk openly with health care providers when the opportunity exists. Farran, Herth, and Popovich concur with Frank’s observation and note that when trying to do (formal) assessments of patients’ hope or hopelessness, finding privacy is a confounding feature that affects how well these assessments can be done; in addition, having adequate time within which to do these assessments and to talk with patients about hope is viewed as critical.

¹³ This reinforces the claims made above that there is a need to not only improve communication, but to consider the various aspects and forms of communication. This includes the physical environment within which these discussions are taking place.

¹⁴ This point casts some question on one of the strategies of Farran, Herth, and Popovich that were described earlier, namely to positively reinforce expressed hopes. Certainly there may be cases in which this reinforcement is appropriate and necessary for a patient to be able to sustain hope; but this strategy should not be understood as a blanket dictum to “always” support particular patient hopes. The time pressures and lack of privacy may account for some of the difficulty in “hearing” hope work in emergency cited above.

The clinical environment is often described as fast paced due to the complexity and number of activities going on simultaneously. Health care professionals, specifically nurses, are often felt to not have enough time to complete the tasks and activities currently required, let alone additional tasks...Privacy is also often at a premium in a very busy and crowded clinical setting...Privacy may play a key part in obtaining a valid assessment and may require changes being made so that the necessary privacy can be obtained. (Farran, Herth, and Popovich 1995, 85)

Thus, at a very basic level, trying to find ways to protect patients' privacy or to create opportunities for privacy as well as trying to address the time stresses that many health care providers are under could contribute to fostering conditions for hope.¹⁵

A related confounding factor in fostering conditions for hope, identified in Frank's example, is ensuring that care-providers are attentive to the messages patients are sent based on the way health care is organized (i.e., that patients "are expected" to share personal information about themselves, even if others can overhear it) and how this can affect whether patients feel that health care providers "really" care about them and their ability to hope or cope with their illness or injury. Being attentive in these ways may be difficult for health care providers due to the commonplace nature of "life in the hospital" for them. The responsibility to foster conditions for hope pushes care-providers to not become complacent about current practices of care and/or to allow the "that's the way it's always been done" explanation to necessarily suffice as justification for not changing something that doesn't work or decreases (the chances for) patient hope. John Bruhn

¹⁵ Certainly I do not mean to imply that just because privacy or time are "basic" conditions needed to foster hope (and will likely have other positive benefits for patients) that these will necessarily be easy to address or find workable solutions to.

provides one example of how complacency on the part of health care providers can affect patient hope:

In the case of hospitalized patients, the environment can convey a sense of hope and support or the opposite. Caregivers may become so accustomed to the environment they work in that they become insensitive to the cues that patients sense in the physical environment and in the interactions among staff and between staff and patients. [Kastenbaum 1971] For example, patients may deduce much about their condition by observing how they are cared for in contrast to other patients with a similar condition in a coronary care or intensive care unit. (Bruhn 1984, 218)

Although it may be difficult for health care providers not to become complacent about practices of care, for example, their familiarity with the setting or a lack of time and support for changing problems with how care is organized, this difficulty should not obviate attending to and evaluating these practices of care. The challenge then is to find ways which will make it easier for health care providers to evaluate their practices of care in terms of their effects on patient hope.

In his discussion of the tension that can exist between care and work in health care - i.e., the tension “between individualized demands of compassion and sympathy and the impersonalized, routine demands of the efficient workplace” (Brody 1992, 66) - Brody lists some important questions that could help inform health care providers about whether certain practices need to be changed. These questions include:

What work routines typify this particular medical-care setting or team of professionals? In what ways might that work routine conflict with the individualized care needs of this patient? To what extent are the involved professionals consciously aware of this potential for conflict? (Brody 1992, 82)

In trying to draw to light the ways in which the organization of the demands of care and of work can affect the suitability of the care that patients actually receive, Brody helps to further this investigation into the fostering of conditions for hope. His questions target practices of care and work, forcing health care providers to consider the ways in which these practices may or may not benefit patients.

A further issue to address with respect to context and the fostering of conditions for hope is to extend our thinking about how this responsibility should be shared between all health care providers. The strategies described above by Farran, Herth, and Popovich are written in the context of nursing practice while Jevne's suggestions are primarily directed towards physicians; although these articles are written for specific audiences, they do help to sustain the impression that what physicians can do and what nurses can do with respect to patient hope is "different" or that hope care can be easily separated among care-givers. While it may be the case that there are some forms of care-giving that nurses are better suited to than physicians and vice versa, the ways in which these individuals can work together to foster conditions for hope should not be overlooked. As the following quote suggests, a team that functions well can provide good hope care for patients when they work together, set goals together, and are aware of what the patient is hoping for.

...[E]xperience suggests that, for these people [those who are dying], hope is not related to cure or long-term remission. Rather, it describes a quality of personhood—of being loved, accepted, and valued despite, not because of, all that is happening. Hope changes day by day, is a personal thing unique to each patient, is usually difficult to articulate, but is always worth speaking about. The professional carers who can work together, set and regularly define goals, and

always know what today's hopes are for their patient—they are a true [palliative] team. (Doyle, Hanks, and MacDonald 1998, 817-818)

In addition, taking a team approach to patient hope means that health care providers will often be able to find support from each other for their hopes and/or be better able to care for a patient that is despondent or difficult to deal with.¹⁶

[In working with a patient who expressed great despair]...we relied on the whole health team for relief and peer support. We used part of our weekly care conferences to help us overcome our own feelings of inadequacy and hopelessness, and found that each member's hope inspired others [Limandri and Boyle 1978]. (Bruhn 1984, 218)

One of the overlooked aspects in discussions of how to enhance patient hope is that emotional support for health care providers themselves from, for example, other team members may be critical. We need to remember that, "...the care giver-recipient dyad rarely exists in isolation from other relationships; the care giver is generally nested in a cluster of relationships from which she can in turn draw care." (Carse and Nelson 1996, 22) Finding ways for health care providers to draw upon and encourage these support networks may be useful for lessening the "hope care" burden on each individual care-giver. Of course, there may be conflicts between members of the team as to how best to foster conditions for hope and/or what is considered to be a reasonable hope for a particular patient. How these conflicts are resolved or addressed will make a difference to patient hope; recall the discussion in Chapter Four about the decision by a physician to not tell a patient her diagnosis at the family's request. This had an impact on how the nurses

¹⁶ This reminds us of the importance of attending to health care providers' hopes or, at least, the support they will have to foster conditions for patient hope.

were able to care for the patient (they withdrew from her) and this, likewise, had an impact on the patient and her hope. This represents another contextual feature - how conflicts about care are resolved - that relates to the responsibility to foster conditions for patient hope.

In this short overview of some of the contextual factors that impact upon the ability of health care providers to meet their responsibility to foster conditions for hope, I have demonstrated that attending to patient hope requires more than improving communication with patients and/or employing hope-specific strategies. Considerations of time, privacy, team medicine, and how conflicts are dealt with among team members are just a few of the contextual elements that are relevant to what care patients receive as well as to the adequacy of this care for meeting patients' hope needs. As Frank's example about the lack of privacy demonstrated, even if health care providers do attempt to talk to patients about hope and/or employ some of the suggested strategies, contextual features of health care's organization and delivery can negate these efforts. Not surprisingly, these "practical" aspects of providing care are ones that appear in a number of discussions about improving patient-health care provider relationships as well as re-structuring health care (see, for example, Purtilo 1988). As such, attending to patient hope provides yet another reason to change and re-organize how health care is delivered and I will extend this analysis in Section 6.4 below.

6.3.4: Summary

What have we learned from this relatively quick overview of some of the strategies

suggested in the hope literature for enhancing patient hope, health care providers' own hopes, and contextual features that have an impact on fostering conditions for patient hope? First, and most importantly, in order to best fulfill their responsibility, health care providers need to address patient hope in all aspects of patient care and not only when "problems" with what a patient hopes for exist.¹⁷ As Sue Campbell argues in her book, *Interpreting the Personal: Expression and the Formation of Feelings*, an individual's emotions are affected by the uptake, or lack thereof, by others. As such, problems arise if we are not attentive in moral ways to the emotions of or expressions of emotions by others.

I have argued that what we feel can be individuated through expression to sympathetic interpreters and can be distorted or constricted in interpretive communities that are unsympathetic. The necessary public nature to expression gives others ways of controlling our affective lives. (Campbell 1997, 165)

...because of the relation of feeling to significance, when our feelings are trivialized, ignored, systematically criticized, or extremely constrained by the poverty of our expressive resources, this situation can lead to a very serious kind of dismissal—the dismissal of the significance to a person of his or her own life, in a way that reaches down deeply into what the significance of a life can be to the person whose life it is. (Campbell 1997, 188)

Health care providers can both positively and negatively affect patient hope; even if they support what a patient hopes for, health care providers can still destroy this hope by not being aware of how what they say and do can affect patients. Campbell clearly articulates

¹⁷ This coincides with the comments I made in Chapter Five about health care providers needing to shift from a "reactive" to a "proactive" approach with respect to patient hope.

the danger of an individual's feelings being ignored or distorted - the significance of this feeling to the individual's own life and the significance of her life itself is dismissed. As I have argued in this work, the role that hope plays in the lives of patients (and health care providers) must not be overlooked nor underestimated. Hope makes a difference in how well people live their lives and, given this, what patients hope for must be "sympathetically" heard or interpreted and factored into all aspects of their care. As I just discussed, there are actions that health care providers can take now that will have a positive impact on the conditions for patient hope.

Second, the context within which this responsibility of health care providers arises has an important role in both the understanding of this responsibility and what measures are considered and employed for meeting it. In other words, attending to the context of health care is important since the context can influence whether health care providers attend to patient hope, what their attitudes and beliefs are regarding hope, and what the practices of care are. The "context" of the responsibility to foster conditions for patient hope can be discussed from a variety of perspectives; above I examined how the hopes of health care providers can affect how the responsibility is understood as well as how some of the concrete aspects of health care's organization and delivery, such as time constraints and privacy, can impact on patient hope. And yet, I have not gone far enough in discussing the context. In focusing primarily on health care providers in their roles as care-givers and as supporters or backers of patient hope, I have said little about how the practices of care that currently exist and the choices that health care providers can make about (hope) care for patients are both encouraged and constrained by choices made by others (those who

are primarily in a position to care about and to take care of) and by the social context in which health care is practised. As Margaret Urban Walker reminds us:

What goes on morally between people is constrained and made intelligible by a background of understandings about what people are supposed to do, expect, and understand...Self-direction, responsiveness to others, and mutual accountability are constant tasks in human social life, but the ways that human societies shape these vary. (Walker 1998, 10)

6.4: “More Distant” Others and the Social Context - Implications of the Care Approach

Attending to the context within which patients and health care providers interact is a necessary part of discovering how to best foster conditions for patient hope. Being aware of the demands on health care providers and how fulfilling the responsibility to foster conditions for patient hope (and their own hope) may exacerbate what is presently expected of them draws us to consider the “big” picture - namely, to consider the role of “more distant” others and prevailing social attitudes or ideologies in the conditions that may be fostered for patient hope. Thus, in this section, I make the transition from focusing primarily on what health care providers can do to foster conditions for patient hope to focusing on how attending to hope can link up with the broader critiques of how health care is organized and delivered. And, if changes are made at these higher or broader levels, an increased ability to foster conditions for hope will be among the benefits.

In Chapter Four, Section 4.2 when I discussed the vulnerability of patients with respect to hope, I suggested that administrators, insurance companies, hospital boards,

and government officials can all make decisions that affect what services are available for patients as well as affect what health care providers can and can not do. In making these decisions, these “others” send messages about what is valued and what is not; these rankings of values inform health care providers about what they should focus on in patient care and how they should address the variety of patient needs they are faced with.

Noticing the connections between these more distant others, health care providers, and patients indicates that these other individuals and groups do bear some responsibility for patient hope. Indeed, both Walker and Tronto stress the interconnections that exist between people and how these interconnections can create responsibilities to be aware of and respond to the needs of others (even if these responsibilities can be deflected in some cases).

Feminist care theorists such as Tronto contend that if we start to take care seriously, this will require changes to how our society currently operates and, relatedly, to how our social institutions are structured and run. She points out that there is frequently a separation between those who care about and take care of and those who give and receive care. The implications of this separation of the different aspects of care are important when thinking about the fostering of conditions for hope. For example, ensuring that those who primarily engage in the activities of “caring about” and “taking care of,” such as insurance companies and the government, make decisions that actually take the needs of care-receivers and care-givers into account will be difficult. They must find ways to represent these needs properly and also find the “best” way to meet those needs; for example, how should the health care budget be spent? As Tronto points out, there is a

prevailing ideology that militates against these “others” taking responsibility for the outcomes and effects of their decisions that presents a further complication:

Generically, those who are responsible for “taking care of” a problem, and perhaps spend money to alleviate a problem, do not feel that they need to supervise the interaction of care-givers and care-receivers. If care-receivers feel aggrieved, they cannot complain to those who have not provided the direct care, because that is not their responsibility. Dividing up responsibility privileges those who are excused by not needing to provide care; thus the privileged avoid responding directly to the actual processes of care and the meeting of basic needs. (Tronto 1993, 121)

Decisions made about funding for health care and about how these limited dollars will be spent says much about what is valued and about how different goals in terms of health/illness vary in importance. Where does and should hope fit in in the larger picture of decision-making about health care? Consider Ronna Jevne’s vision of what health care could be if it were structured and organized with hope, and care, as its main focus:

I have a dream – a vision of how caring could be...That it could mean coming to an institution that cared - not just one person caring – not just an individual nurse, a unique doctor, a gentle orderly. Where a whole institution of caring people understood that nothing is as therapeutic as recognizing the pain, not only the physical pain...I have a vision that caregivers would share a strength – a strength that comes only from a common purpose. That comes from belonging to a community – a community of people who believe – who believe that caring makes a difference. (Jevne 1993, 129)

Creating, or working towards establishing, health care institutions that are able to care for patients in the sense that Jevne describes or are able to work towards achieving the ideal of care as Tronto envisions clearly extend beyond the types of considerations about patient

hope that I have addressed in this dissertation.

And yet, if we take hope seriously and ask health care providers to be responsible for fostering conditions within which patients can discover and continue to have hope, it seems that this provides an additional reason for making radical changes to how health care is organized and delivered. Although one could argue that the responsibility to foster conditions for hope should be limited by the existing constraints on health care and health care providers should do the best they can within these bounds, we have seen that current practices of care are unable or unlikely to adequately “take care of” patient hope. And, in order to question or change these practices of care, those who are in a position to “care about” hope will have to both play a role in devoting resources to this endeavour and in determining the best way to balance out competing demands for resources.

Good care will also require a variety of resources. Lest the description of care as a practice mislead our thinking, care depends upon adequate resources: on material goods, on time, and on skills. Resources for adequate care will generally be more scarce than those engaged in caring might like; one of the larger political questions to consider is the determination of which caring needs receive which resources. (Tronto 1993, 110)

But, beyond the question of devoting resources or shifting how resources are spent in order to better care for patients (and thereby implicitly for patient hope), there are important ideological and value commitments that must be challenged and changed as well - I will mention a few examples.¹⁸

¹⁸ I have already indicated the need for a shift from a “reactive” to “proactive” approach to patient hope in Chapter Five. Also, consider again the efforts by Kay to teach her staff about manic-depression that I discussed in Section 3.4.1.

It seems that (many) patients are looking for a form of care and connection with their health care providers that is not being fulfilled by the current treatment or cure paradigm. As the ethics of care reminds us, care-receiving is a vital part of establishing and evaluating practices of care; in this case, attending to the hopes of patients suggests that finding the “miracle” cure may be less important than taking the suffering that patients experience seriously and attempting to do something about it - such as foster an environment within which patients can find and discover hope (through caring). Health care providers tend to think primarily in terms of technological and pharmacological treatments as the forms of “help” and “hope” that they can offer to patients. As John Bruhn points out: “Too often, caregivers rely on drugs or the latest therapy to express hopefulness to a patient.” (Bruhn 1984, 218) Health care providers could instead sometimes think about helping patients to live with incomplete or less than “normal” health by, for example, helping them to learn how to cope with a particular illness or injury or to alleviate both emotional and physical suffering. Such a shift would be one way in which health care providers can find and foster conditions for hope.

There are three main approaches that can be taken for helping individuals who are ill or injured. The most obvious approach is to “fix the broken;” that is, to focus primarily on treating those who are ill or injured. Of course, if treatments and/or cures exist, these should be given to patients or, at least, offered; in this sense then, there is nothing wrong with this approach. The difficulties arise, as I discussed above, when an overly technological and pharmacological (and narrow) focus on cure for treating patients is taken. The danger is that if most of our resources and time are devoted to “fixing the

broken,” this means that other necessary approaches to health and illness, such as prevention, are given less attention. A second approach, then, is preventing the damage in the first place. The standard, almost exclusive, focus on “fixing the broken” ignores the overwhelming evidence that attending to preventative measures would greatly decrease the number of people who become ill or are injured. Those who would need the assistance of health care would be substantially reduced if changes were made in how our society is structured and run in terms of wealth distribution, opportunities for employment, clean and safe environments within which to work and live, etc.¹⁹ Catherine Frazee supports this point:

...I do resent the enormous investment of economic and intellectual resources demanded by the pursuit of cures – the high-powered complex that will not be diverted to address the political, environmental, and social conditions that are the primary causes of disability around the world. (Frazee 2000, 42-43)

But no matter how good we become at prevention and at “fixing the broken,” there will still be people who are/become ill or injured. This suggests that a third approach is also required in conjunction with the first two - namely, an approach that focuses on supporting the lives of “the broken.” This approach recognizes: a) that even when patients can be cured or treated, they will often still require assistance with managing their illness or injury; and b) that not all people can be “fixed.” As such, this approach further contends that life can be lived well with disability, illness, or injury.

¹⁹ See, for example, *Women's Health Strategy* by Health Canada (1999). It describes a variety of health determinants that have an impact on health and lists a number of such changes that are required in health care to meet women's health needs.

As health care providers become more involved in fostering conditions for patient hope, it is likely that they will become more aware of how the social and political aspects of our lives affect our ability to hope and what we can hope for, especially in the context of illness and injury. It is possible that this awareness could contribute to the changes in our society and health care system that are required to recognize and appreciate the value of the lives of individuals who are ill or injured, and to change our understandings of what constitutes health and illness/disability. Ultimately, it seems we cannot ignore how the social context affects what will be legitimate opportunities for hope for different people and that changes beyond health care itself are necessary to truly help people to live their lives well (with illness or injury).

6.5 Conclusion

In many ways, this has been a difficult chapter to write - not because trying to further understand the normative implications of the responsibility to foster conditions within which patients can discover and continue to have hope poses greater challenges than those of other chapters - but because it reveals two things. First, while my project has clearly furthered our understanding of patient hope, in some senses it has only “scratched the surface” of what the role of hope in health care is and should be. In trying to outline the various practices of care that health care providers should employ to foster conditions for patient hope, I can make some claims about practices that are better or worse and can demonstrate how the care ethics framework lends itself to evaluating these practices. Yet, much more research is still required in order to fill out the “gaps” I identified with what

we currently know about what conditions will enhance/inhibit patients' ability to hope and influence what they hope for.

Second, this chapter has revealed how trying to determine how (well) the responsibility of health care providers with respect to what patients hope for can be fulfilled has implications that extend beyond the confines of patient-health care provider interactions and even beyond the health care system itself. If the interconnections and interdependencies between people are taken seriously, this means that health care providers will have to attend to how their actions may exacerbate the vulnerabilities associated with what patients hope for, but also that the impact of the organization and delivery of health care as well as social attitudes about health and illness will need to be evaluated as well. As Margaret Urban Walker explains, "...our grasp of vulnerabilities is heavily mediated by background conceptions of well-being and human agency and efficacy, and our understanding of these is shaped as well by familiar practices, institutions, roles, and relations." (Walker 1998, 87)

Ultimately, the message of this chapter is that health care providers do have a responsibility to foster conditions for patient hope and can make changes now to the care that they give to patients. However, the message is also that attending to patient hope is not all about what health care providers do and say; it is also about appreciating the interpersonal connections that exist between people and the vulnerabilities and responsibilities that arise from these connections. The "more distant" others mentioned above do need to take hope into account and acknowledge that the way they "care about" and decide to "take care of" the health care system affects both patients and health care

providers. As Tronto argues at the end of her book, "To recognize the value of care calls into question the structure of values in our society...Care is a central concern of human life. It is time that we began to change our political and societal institutions to reflect this truth." (Tronto 1993, 180) This analysis of the role of hope in health care has demonstrated that there is a need to think about hope, and about health and illness, differently; importantly, we need to appreciate that the type and nature of the relationships that are formed between those in need and those who can provide care can influence how well these individuals are able to live their lives.

Chapter Seven

Conclusion

This is what knowledge really is. It is finding out something for oneself with pain, with joy, with exultancy, with labor, and with all the little ticking, breathing moments of our lives, until it is ours as that only is ours which is rooted in the structure of our lives.

Thomas Wolfe

7.1: A Few Final Thoughts from Patients

Since I began this work by emphasizing the importance of patients' stories, it is only fitting that I end by returning to what patients have to say about hope.

While I primarily used Bonnie's experiences in rehabilitation to demonstrate or flesh out problems with particular practices of care with respect to patient hope, not all, nor even most, of Bonnie's interactions with her health care providers negatively affected her ability to hope. If what I have said about care that meets patients' hope needs is correct, the following example from Bonnie's experiences provides a model of good caring:

I could lift my arms off the bed for seconds at a time, and even though my right foot was still disconnected, I could wiggle my left one like crazy. I still couldn't breathe, eat, pee, sit up, or dance, but surely these would come soon. Meanwhile the nurses did practically everything for me. There was skin care, back care, mouth care, bedpans, massage, bed baths. There was constant checking of blood gases, spirometers, IVs, feeding tubes, catheters and trach tubes. The best time was Rick's shift. He had a flat, nasal, Ontario kind of voice, but to me he sounded handsome and sexy...He'd tell me about his day and what he was doing and what he was going to do next: not profound talk, just talk. "I'm thinking of buying a windsurfer. What do you think? Last weekend I tried [one]...But should I get one? Blink if

you think I need a windsurfer. All right! I knew you'd be on my side..." (Klein 1997, 137)

Although Bonnie lists all of the different forms of care she receives, it is the care that she receives from Rick - his conversations with her - that she recalls as most important and significant. The care Rick gives helps to create a space within which Bonnie can begin to identify and articulate her own hopes for her recovery. Bonnie's sense of self, and how this relates to what she wants for her life, is fostered by being treated as a person who can think and engage with others (even if in a limited way).

In her article, "Body Politics," Catherine Frazee discusses her wish as a child to walk and how this wish has been transformed as she grown up. (Frazee is a "flaccid paralytic, suffering from a genetic mutation that causes profound and progressive wasting of the skeletal muscles." (Frazee 2000, 41))

A lot of life has been lived - and lived well - ...[in a wheelchair]. Such an abundance of felicitous living warrants careful thought about what it means not to walk. The simple arithmetic of it is that my disability has brought me to all of the things I value - my career, my friendships, my creative life, my skills, my tenacity, my intimate partner, my world view. And there is no logical reason to believe that this will not continue to be the case for as long as I remain alive. (Frazee 2000, 42)

Those of us who are able-bodied have difficulty imagining not being able to walk, and most would not want to live their lives in a wheelchair, but as Frazee demonstrates not everyone in a wheelchair hopes for the ability to walk. Frazee emphasizes how hopes (and wishes) can change over time and with experience; even if one's most precious hope cannot be realized, one can survive the loss of this hope and find new things to hope for.

Frazeo has found value in her life and lives her life well, but she is not resigned to her “position” in society as a person who is disabled.

This is not a matter of simple acceptance, of stoicism, of bravely making the best of my sorry lot. It is a matter of growing into and embracing my experience of disability. This is not to say that I embrace the exclusion, the stigma, the devalued status, the abuse, and the barriers that are the constant companions of disability. These I reject categorically. (Frazeo 2000, 42)

Even though Frazeo relates how she has come to embrace her experience of disability, she makes it clear that there still are attitudinal and structural barriers in society that do affect and influence her life and those of others with disabilities (and illnesses). In other words, Frazeo reminds us that fostering the conditions for hope is not only something that needs to be done in medicine, but extends to our society as well. If we are to truly support the lives of individuals with illnesses, disabilities, and injuries, then we each bear some responsibility for recognizing these barriers and working to change them.

7.2: Future Directions

In the following, I will sketch out some of the possible future directions for (theoretical) work on the role of hope in health care. These future directions can be best grouped together according to three main questions that may be asked at the completion of this project.¹

First, one can ask *who* has been left out of this analysis of hope in health care? As I

¹ Of course, there are more future projects than what I will describe here. I have chosen what I take to be three projects that stem from my analysis of hope.

stated at the outset, my focus in this project would be primarily adult patients and health care providers. The most obvious “who” that has not been discussed are the family and friends of patients. What is the role of family and friends in what a patient hopes for? It is often the case that these individuals can help support the patient and help her to sustain her hope(s). Indeed, in stressing the importance of relationships and interactions with others in patient hope, family and friends may play just as important a role in what patients hope for as health care providers do. But, to what extent should the health care provider be concerned with what these individuals hope for and suggest to the patient? Is the health care provider responsible for redirecting the hopes of family and friends if these hopes can be legitimately contested? Answering this question may rely on the extent to which the family and friends influence or put pressure on the patient to maintain a particular (problematic) hope and/or whether what is hoped for could cause harm to the patient. It is also possible that the family or friends may put pressure on the involved health care providers to not tell the patient “bad news” in order to sustain the patient’s hope that she will get better or that she doesn’t have cancer. What are the health care providers’ obligations and responsibilities to the patient and to the family and friends in these types of situations?²

Another “who” that has been left out is self-help or support groups which play a crucial role in many patients’ lives as they deal with their illness or injury. Being able to

² This line of questioning leads into concerns and questions about truth-telling to patients and the role of cultural differences in making decisions about what to tell patients. I will not speak further to this issue here, but see, for example, Surbone 1992 and Pellegrino 1992.

talk and to share with others who understand what you are going through can be a powerful and healing experience. As Sharon Batt says of the Breast Cancer Action Montreal group, "This knitting together of acute pain and happiness is precisely what satisfies me most deeply about the formation of our group. Becoming part of a collective entity brings comfort. No longer isolated, we all gain strength." (Batt 1994, 325) Learning more about the role these types of groups can play in the ability of patients to hope would, for example, include: a) how these groups do or do not influence what the members hope for; and, b) how different structures or organizations of these groups affect (the discussion of) hopes. In addition, exploring in more depth the connections these groups do or do not have with health care institutions, and the reasons why, may provide useful information about the conditions for hope in health care.

Second, one can ask whether my analysis of hope will apply to other clinical contexts? In focusing primarily on patients' stories from four clinical contexts to conduct my analysis of hope, this means that it will be important to test both my definition of hope and my formulation of the responsibility for health care providers in a variety of other health care situations. How, for example, does the responsibility to foster conditions for hope play out with respect to the new reproductive technologies? It seems obvious that this enterprise is founded on the hope that, with assistance, women will be able to become pregnant and maintain these pregnancies. Despite the low chances of success, many women and couples are willing to pay the money, suffer the emotional highs and lows, and bear the physical intrusions. Many women who make use of these technologies strongly hope for a child and this hope may sustain them through many failed attempts and/or lost

pregnancies. But we can't ignore both the ways in which social pressures influence women's choices about having children and the ways in which the hope for "success the next time" can be played upon by those with a vested interest in these technologies. Does fostering conditions for hope in this clinical context mean that health care providers should challenge or try to correct for these social pressures?

Another important context within which to explore the adequacy of my approach to hope is pediatrics. Hope (for a child's cure or survival) looms large, for example, in neonatal care, pediatric intensive care, and pediatric oncology. It often seems that the focus is on doing anything and everything in order to help the baby or child survive; the hopes invested in children seem particularly strong and motivating for both parents and health care providers. William Ruddick describes these as "vital" hopes which are hopes,

...that give shape and meaning to a life. For many people, their children (or hopes for children) are such vital, life-defining hopes. The death of a child deprives parents of those vital hopes and rationale for living. If they are to go on living, they must find or renew other vital hopes. We might call these 'survival hopes' in that [they] are needed to survive the loss of people who have been the basis of our most important vital hopes. (Ruddick 1999, 353)

Thus, Ruddick captures how important hopes for their children are to parents and how difficult it may be to find or renew hopes after a child's death, i.e., to find those survival hopes. Ruddick further suggests that how the child dies may make a difference to whether parents are able to carry on and that feelings of guilt, betrayal, and regrets may need to be considered and dealt with by parents (and by the involved health care providers) (see Ruddick 1999, 353-354). Clearly, the main difference between the account of hope I have

given and the role of hope in pediatrics is that there is a triadic relationship to consider - the parents and health care providers have hopes about a child and yet the child herself, if very young, does not have her own hopes. Does this affect my account of hope? And, as children get older and are able to participate more in decision-making about their own care, what influence will children's hopes play in how they approach and/or make decisions? Very little is known about the hopes of children and how what they hope may relate, for example, to their understanding of death. If family-centered medicine continues to be fostered and encouraged in pediatrics, it seems that learning more about the hopes of children, the hopes of parents, and the hopes of health care providers in this clinical setting will provide valuable insight into what conditions would work best with respect to taking account of patient/parent hopes.

Third, one could ask how this responsibility to foster conditions for patient hope relates to other responsibilities and duties that health care providers have? The duty to disclose information to patients or to tell patients the truth is the duty most often thought to conflict with promoting or maintaining patient hopes. But as Howard Brody argues:

...setting hope-maintaining against truth-telling is to create a false dichotomy. There is no fundamental conflict between our moral duty to preserve hope—to heal our patients with our words and not just our medicines—and our moral duty to respect our patients as adult human beings who should be given the information they need to make their own free choices about their lives. (Brody 1981, 1412)

Focusing on *what* needs to be told (the “truth”) and pitting this against what a patient hopes for overlooks the importance of attending to *how* the information will be told. In many ways, Brody's argument concurs with my contention throughout this work that it

makes a difference how health care providers attend to patient hopes. Although telling the truth to patients in some cases may destroy particular hopes, this does not entail that the patient needs to or will be left without any hopes (especially if attention is given to the best way to communicate this information). Thus, it appears that the supposed conflict between truth-telling and patient hope may be resolvable. However, it would be worth exploring this issue further in a variety of situations where difficult information needs to be told in order to better understand the effects of “bad news” on patient hope and what communication strategies are most effective for helping patients to find, for example, new hopes.

A further twist on this issue of hope and disclosure is suggested in the above quote from Brody; namely, how does hope relate to the ability of patients to make choices about their life? In other words, what is the relationship between fostering conditions for patient hope and supporting patient autonomy? It has often been charged that maintaining hopes in patients has led to deception or the telling of half-truths, making it impossible for patients to make informed decisions about their health care and about their lives. As such, it would seem that allowing a patient to hold onto a “false” hope or deceiving a patient about the chances that her hope will be realized would contravene this patient’s autonomy. But is this necessarily the case? William Ruddick argues that how we understand autonomy may make a difference to how we understand the role of hope in patients’ lives. For example, if we understand autonomy, not primarily in terms of making informed choices, but in terms of “living the life one embraces,” hope can make a difference to whether people can continue to live their lives.

[If patients are told the truth about their impending death and their hope for cure is lost]...patients may become preoccupied by regrets about what they have or have not done in the past, or on what they will not live to see in the future. Thereby, they may cease attending to the people and projects that define the lives they have long been leading. (Ruddick 1999, 347)

Ruddick goes on to argue that if a physician can only support a patient's autonomy (the capacity to continue with one's life-defining activities) by withholding the truth and maintaining a false hope, then this may be justifiable in certain circumstances (see Ruddick 1999, 348). This is a contentious claim that will not sit well with some advocates of patient autonomy. However, the claim Ruddick makes is important for it challenges us to consider more deeply the connection between emotions, such as hope, and a person's autonomy. And at this juncture, it may be appropriate to draw upon accounts of relational autonomy given that these accounts,

...are premised on a shared conviction, the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity. (Mackenzie and Stoljar 2000, 4)

As such, relational autonomy may help inform the discussion of what the health care providers' role should be in supporting both patient autonomy and patient hope.³

³ Related issues to explore would include self-deception and denial as opposed to deception by others and how this connects to hope and autonomy. I do not want to eliminate at the outset the possibility that denial, for example, may play a key role in helping a patient to adjust to a life changed by illness or injury. Further, one could question whether health care providers should have a role in assisting a patient to change her values and/or goals if these are not contributing to her autonomy and/or her ability to hope for some state of affairs; i.e., to what extent can health care providers help patients in the process of self-understanding and self-definition (or re-definition) that may be part of a

These are just a few of the future directions in which this investigation into the role of hope in health care can be extended. Clearly each project will raise difficult and interesting moral questions about how to understand the health care providers' responsibility to foster conditions for hope as well as how it extends: (1) to others involved in a patient's life; (2) applies in other clinical contexts; and, (3) relates to the other duties and responsibilities health care providers have.

Let me finish this project with an excerpt from a poem written by a woman whose husband has AIDS. The poem gives her perspective on her husband's illness and shows how complicated finding and sustaining hope can be. Inger emphasizes the importance of considering family and friends, and what they hope for, when a loved one is ill or injured.

The Flame of Hope

It trampled into the security of our family life
transforming everything in a moment
A chaos of emotions -
surprise, tension, fear and not least, hope.
Medical examinations.
A stay at the hospital.
It lasted a long time, I thought back then.
Three weeks of need, fear and hope.
Then a couple of years where it
Almost seemed as if nothing happened.
Then suddenly it returns.
The hospital and examinations.
Fear - could it be that?
Hope - no, no, it probably isn't.
Barely a couple of months later.
The results.
The shock - it wasn't that.
Surprise - it can't be true.
Fear, but still hope.

patient's experiences with her illness or injury?

The weeks pass.
A weekend visit at home.
Possible discharge next week.
Relief - it worked.
But no - in a flash, everything's changed again.
Crisis.
We wait - for what? Life or death.
Still - fear and hope.
Then one day
It worked - we made it.
Home again...
(Inger 1992, 153)

Appendix: Stories of Hope

This appendix contains the references for and a short synopsis of the “hope stories” I have collected while working on this dissertation. Some of the cases are mentioned in my dissertation and some are not (the former have a star after the reference).

Albom, Mitch. 1997. *Tuesdays with Morrie: An old man, a young man, and life's greatest lesson*. New York: Doubleday. (*)

Mitch is given the special gift of being able to reconnect with his former mentor, Morrie Schwarz, after Mitch hears an interview with Morrie on “Nightline.” Morrie has amyotrophic lateral sclerosis and is in the last few months of his life, yet he is still able to teach Mitch about what it means to live. And through this simply written story, Mitch shares what he has learned.

Call, Deborah A. 1997. Living with a chronic illness. *The Seattle Times*. Wednesday, July 2 (Special). <http://www.seattletimes.com/extra/brwose/htm197/altchro_o70297.html>

The title of this article says it all - living with a chronic illness, in this case scleroderma (an autoimmune disease in the arthritis family), is described by Deborah. She explores the impact of her illness on her self-image, having to relearn simple tasks, accepting limitations, and the role of support groups.

Carver, Raymond. 1989. What the doctor said. *A New Path to the Waterfall*. New York: The Atlantic Monthly.

In this poem, we get a glimpse into what the patient hears and thinks when he is being told “bad news.” Even though it is clear that the patient has cancer, this word is never mentioned.

Diamond, Shelley. 1997. Doctors, compassion, and chronic illness - Dear Dr. H. *Eczema Mailing List*. Posted August 9. <<http://www.pinch.com/skin/docs/deardrh.html>> (*)

In an open letter written to a physician, Shelley expresses her rage and frustration at being treated as just another patient. Her suffering is not acknowledged and little support is offered to her. She issues the challenge to physicians generally to learn how to better treat persons with chronic illnesses.

Dime-Meenan, Susan. 1994. My journey back to sanity. *McCall's*. October. <<http://www.mentalhealth.com/story/p52-bi0l.html>>

A story that conveys the anguish experienced by a woman with manic-depressive illness who was not diagnosed until she was twenty-seven. From a difficult adolescence to

a rocky marriage and escalating symptoms, Susan's commitment to a psychiatric ward was the turning point.

Duke, Patty and Gloria Hochman. 1992. *A brilliant madness: Living with manic-depressive illness*. New York: Bantam Books. (*)

In this book, the reader gets more than a glimpse into the "real" life of a famous actress who has manic-depressive illness. The ups and the downs are vividly described along with their impact on those who live with and care about Patty.

Frank, Arthur W. 1991. *At the will of the body: Reflections on illness*. Boston: Houghton Mifflin Company. (*)

Arthur had a heart attack at age thirty-nine and was diagnosed with cancer at age forty. In this book, he reflects on the "impact" of serious illness. What makes a difference to suffering, to being able to recover in spirit, in mind, and in body? Exploring such issues as the stigma attached to some illnesses, the value and valuing of illness, and the expectations and assumptions made in health care about the experience of illness, Arthur shares the lessons he has learned and presents the reader with some important challenges.

Frazer, Catherine. 2000. Body politics. *Saturday Night*. September 2: 40-43. (*)

Catherine considers her "wish" as a child to be able to walk from the vantage point of her life now at forty-six. Considering such things as the "ideological underpinnings of the cure industry" and her own contradictions and inconsistencies as an activist, Catherine challenges the reader to think more about, and potentially revise, her own assumptions about what it means to be able to walk.

Jamison, Kay Redfield. 1996. *An Unquiet Mind*. New York: Alfred A. Knopf. (*)

Kay is a professor of psychiatry at the Johns Hopkins School of Medicine and is well-known for her research on mood disorders, suicide, and lithium; indeed, she is recognized as one of the foremost authorities on manic-depressive illness. Yet, her interest in this illness is more than professional as Kay herself is manic-depressive. In this book, Kay tells us the story of her illness relating tales of manic episodes and devastating depressions. Kay's interweaving of her experiences with her professional practice and research provide a compelling insight into the lives of individuals who have manic-depression.

Jones, Richard. 1986. The waiting room. *Country of Air: Poems by Richard Jones*. Port Townsend, Washington: Copper Canyon.

This poem talks about the patient's experience of being in a waiting room, waiting

to see the physician and wondering what will happen.

Klein, Bonnie Sherr. 1997. *Slow Dance: A Story of Stroke, Love, and Disability*. Canada: Vintage Canada. (*)

Bonnie is a film maker and producer who suffers a relatively mild stroke, begins to recover from it, and then suffers a second devastating stroke a month later. This story written by Bonnie includes excerpts from her patient chart, reflections from family members and friends, as well as comments that were written in a visitor's journal during her lengthy hospital stays. We follow Bonnie from her initial disbelief at having a stroke through the anxiety attacks in intensive care to the rehabilitation center and her return home. Bonnie also shares her insights into what her life is now like, in terms of her work, the challenges she still faces, and who she is.

Krauthammer, Charles. 2000. Restoration, reality, and Christopher Reeve. *Time* 155(6): February 14: 100. (*)

As a physician who has a spinal cord injury, Charles challenges the message sent by Reeve's in his Super Bowl ad proclaiming the "cure" is just around the corner. Charles contends more thought needs to be given to the harm that holding onto this hope may bring for those with spinal cords injuries, particularly the newly injured.

Lyn, Darcy. 1994. *Myself resolved: An artist's experience with lymphoma*. Philadelphia: Meniscus Health Care Communications. (*)

Darcy traces the course of her illness from its initial symptoms to the diagnosis of lymphoma through her treatments and recovery. Concurrent with this, the reader learns about Darcy the artist and how this Darcy "sees" her illness and her health care providers (she does paintings of her three primary physicians as well as some of the nurses). An honest account of having cancer; the reader is reminded of both the special joys that can come from caring and the great fears that can come from uncertainty or harshness from others.

Mozersky, Judy. 1996. *Locked In: A Young Woman's Battle with Stroke*. Ottawa: The Golden Dog Press.

Judy suffered a totally incapacitating stroke at the age of nineteen; she was unable to control her body, yet could still think. Hence, she was "locked in" her body. Despite the odds, Judy managed to regain the ability to breathe on her own and is now living in her own apartment in Ottawa. She has told her story in this book by "blinking" it out letter by letter.

Schmidt, Stephen A. 1996. When you come into my room. *Journal of the American Medical Association* 276(7); August 21: 512. (*)

Stephen has Chron's disease and has spent much time in hospitals. In this article, he shares the types of things he feels health care providers should know (or at least make an effort to know) "when they come into his room." Obviously much more than the typical medical history is expected.

Wassersug, Richard. 2000. Flossing for the future. *The Globe and Mail*. Tuesday, August 22: A14.

Using the question "How are you?," Richard introduces us to the changes that have occurred in his life since he had an elevated prostate specific antigen (PSA) test and was diagnosed with prostate cancer. Trying to and learning how to live his life while waiting for the next PSA result, Richard has decided that his goal is to do something each day that pertains to the long-term future (whether he will reach it doesn't matter). Hence, he has chosen to "floss for the future."

Weiner, Jonathan. 2000. Curing the incurable. *The New Yorker*. February 7: 64-73.

Jamie Heywood's brother, Stephen, is diagnosed with amyotrophic lateral sclerosis and life changes rapidly thereafter. Jamie moves his family, quits his job, and devotes his time and energy to building a research team that will help to realize the hope of cure (or at least amelioration) for ALS in gene therapy. Jamie's devotion, as well as strong support from other family members, means that Stephen can focus on living his life knowing that others who care are doing what they can to help.

Weschler, Lawrence. 1999. The furniture philosopher. *The New Yorker*. November 8: 66-79.

The short summary of this article captures its essence: "Living with the constraints of Parkinson's, Ed Weinberger has achieved the physically impossible--both in life and in art." (66) Absorbingly written, the reader is taken through Ed's life and his struggle to design furniture within the confines of his illness.

Woolf, Colin. 1999. Let's talk Doctor: Death teaches a lesson. *The Medical Post* 35(30): September 14.

Colin has been diagnosed with metastatic cancer and, as a recently retired physician, has learned something about what it is like to be "on the other side." Colin has learned that, despite receiving excellent medical (read technical) care, something was still missing. The missing element is concern by his health care providers about the "psychosocial" aspects of living with cancer. Colin reflects that he ignored these aspects

with his patients and asks some hard questions, for example, about why “we” prolong life with suffering. See also: Valpy, Michael. 2000. Right to die: Ill doctor wants law to allow physician-assisted suicide. *The Chronicle-Herald*. Saturday, Febraury 12: C5.

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