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Exploring Patient Perspective At End Of Life: Qualitative Interviews With Terminally Ill Patients

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**Exploring Patient Perspective at End of Life:
Qualitative Interviews with Terminally Ill Patients**

Thesis submitted to Yale School of Medicine

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2012

Abstract

EXPLORING PATIENT PERSPECTIVE AT END OF LIFE. Kim T. Nguyen and Margaret A. Drickamer. Section of Geriatrics, Department of Internal Medicine, Yale University, School of Medicine, New Haven, CT.

This study examines the thoughts and feelings of patients facing terminal illness through qualitative interviews. To give patients the most agency in forming their stories, we do not frame the investigation with a specific hypothesis. By having open-ended discussions with patients without structured questions, we allow the patients to provide the content on which we form further questions and hypotheses. We interviewed 15 patients with terminal illness, beginning each discussion by asking them to tell us about their thoughts during this period of their lives. We examined the interview transcripts and identified 15 topics commonly mentioned during the interviews: quality of life, course of illness, approaches to treatment, personal goals, hopes, fears and worries, decisions of daily living, place of living, family, prior experiences with death and dying, religion, timeframes, memories, attitude and emotion toward dying, and adjustment. After recognizing these categories, we reviewed what patients said regarding each category and identified themes. While these vary depending on the topic, one overarching theme centered on self-identity. We found that many patients possessed a strong sense of self, which was changed by illness. Much of patient experience with terminal illness was related to how the illness affected their identities, and subsequently how they strive to preserve their identities throughout end of life. Care providers can benefit from this information in several ways. Recognizing what patients discuss most in these interviews can help providers focus on areas of importance in their discussions with patients. Understanding patient experience in the context of their thoughts and feelings, particularly those framed by their self-identities, can improve patient care. Gaining familiarity with the framework in which patients perceive themselves and their illnesses can help care providers better address patient needs and concerns.

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For him, and for the patients and family members interviewed in this project, this thesis is written. Thank you for sharing so much. I hope to share what I have learned from your stories in every day of practice and life.

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Introduction

As care providers, physicians are responsible for examining the breadth and depth of the meaning of “care,” and of the means of providing it. In doing so, they expand the boundaries of care in many directions. No longer solely restricted to the goals of eliminating illness, health professionals recognize the importance of supporting patients through incurable disease. End-of-life care grew largely from the advent of chemotherapy and novel ways to keep people alive longer through life-threatening illness. As Dr. Atul Gwande notes in “Letting Go,” dying has shifted from an acute event or a short interval between diagnosis and death, to a less-defined period of time that may span months or years.¹ When new life-prolonging treatments were developed for illnesses previously left untreated, end-of-life care initially focused on managing the side effects of these treatments.

It was also during this time that patients began to recognize that, unlike in the past when they had few options for managing illness, they now had a choice between treatment and no treatment. And unlike in the past, they now have time to consider and life to live while they are choosing. Confronting this choice and this life brought to light a goal different from merely staying alive longer: the goal to live in a way that one finds worthwhile.^{2, 3, 4, 5, 6} With that goal come the questions of how to define worth and how best to achieve it.

This is where the focus of end-of-life care should lie. As the realm of care has broadened from sustaining life to sustaining quality of life, attention has increasingly been given to the *process* of death and dying. The end of life, a place previously viewed as outside the jurisdiction of physicians who have been trained to help patients get “better,” is now seen as an important part of patient care. Physicians are beginning to consider in thought and incorporate in practice the philosophy set forward by Cicely Saunders, the physician who founded hospice on the

principle that “You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”⁷

Whether a physician is teaching a 39-year-old how to manage his health to prevent coronary artery disease; resuscitating a 62-year-old to save him from dying from a heart attack; or administering oxygen to an 87-year-old to provide symptomatic relief as he becomes terminal from irreversible heart failure, the overarching goal is to give patients the maximum means to lead the lives they find most worthwhile. In all of these cases, physicians can and should address the physical and emotional well-being of patients. Care providers have come to see the period of end-of-life as being similar to other stages in illness in its need for such support.

Because this is a relatively new area of care to receive attention, even physicians who recognize its significance may be unsure of how to address it. This can be seen in the ongoing discussion on when to discuss transition to hospice, and what hospice can do for patients. Care providers have expressed the need for more understanding of how best to discuss hospice, and the underlying issue of end of life.^{8, 9, 10, 11} This is why our study focuses on enabling patients to help us develop care suited to their needs. By speaking to patients about their experiences with life-threatening illness, we learn about the context of their lives, which largely determines how they would like to approach the end of their lives.

In seeking guidelines for end-of-life care, studies have examined patient preferences and perceptions concerning death.^{12, 13, 14, 15, 16} While much remains to be learned, these inquiries into patient perspective offer valuable information regarding how to provide patient-centered care for the terminally ill. By looking at these studies, we can learn from their findings as well as identify areas to explore in greater detail or with a different approach. Underlying this process is the belief that the broad goals of patient care can be applied to the specific aims of end-of-life

care. However, it is important to recognize that relationship also works in reverse. That is, examining patient needs at end-of-life can reveal principles for patient care in all phases of health and life. Indeed, the end-of-life may comprise a unique viewpoint from which to explore patient concerns. During this time, patients may come to realize or express sentiments they did not articulate in the past, whether because they had not been asked about them or because they themselves had not yet given them conscious thought.

One area of care that end-of-life brings into view is decision-making. When confronted with the prospect of death, patients begin to perceive their past and current life within a different framework. Amidst patients' personal concerns, physicians are responsible for addressing decisions like code status, the purpose of medical treatment, and quality of life. In handling such matters, it is important to first recognize that patients' life view, what could be termed their frame-of-reference, may be affected by the idea of death; and secondly to elicit understanding of this process in order to best shape care according to patient perspective. As Yedidia and MacGregor note in their emphasis on shared decision-making, healthcare providers should ensure that patients play a key role in the decision-making process.¹³ This requires more than asking patients to make the choices; it entails understanding their perspectives regarding life, dying, and death, such that providers can converse with them about how their options align or do not align with patient preferences. Awareness of patient experience enables providers to offer more nuanced, individualized care. For example, if providers recognize helpful means of coping in their patients, they can encourage them; if providers see that patients pursue lines of thought or action that would interfere with the patients' stated goals, they can explore the conflict with the patients.

This exploration of patients' philosophies, coping mechanisms, and priorities is

something that should be developed throughout a patient's life and healthcare. Just as an understanding of patient perspective is useful in making end-of-life choices, it is helpful in working with patients to guide their care at any stage of health and illness. However, these issues are often only explicitly addressed at end-of-life due to the decisions that need to be made. It is important to use what we learn from patients at end-of-life to better address their care throughout life. To do so, we first consider how to learn more about patient concerns at end-of-life.

Several methods have been employed to gain information about patient preferences when faced with life-threatening illness, each offering unique advantages and disadvantages. These studies are all qualitative to a degree. To understand why this is the best approach to studying end-of-life experience, it is important to define qualitative research. While it is easy to define qualitative research by what it is not (quantitative), it is important to define the value of qualitative research for what it is. Creswell defines qualitative research as “an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem.”¹⁴ The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting.” This describes qualitative research in terms of both its subject and its methods of studying the subject. When the research concerns a question of human experience, it is useful to approach such a rich and nuanced subject with equally rich and nuanced methods. As such, qualitative methods are best used when a study is interested in the more subjective questions of *why* or *how* than the more objective questions of *what* or *how many*.¹⁵

In healthcare, qualitative research is necessary in order to understand how patients experience their illness, outside of the concrete physical symptoms and laboratory values. It was

anthropologists and sociologists—researchers interested in the human component of experiences—who began exploring qualitative methodology in healthcare in the 1960s and 70s.¹⁶ More recently, researchers within the healthcare system itself have been employing qualitative methods to better understand their patients and improve patient care. There is a growing body of literature on different methods of obtaining qualitative data: interviews, focus groups, and observation, as well as combinations of these approaches.

With a variety of ways to attain qualitative data, the first question when conducting a qualitative study is to decide how to collect the data. The nature of the research question determines the method used to answer it. When concerned with patient perspective and experience, it is important to consider how to elicit both breadth and depth of information. While surveys such as those discussed in the introduction provide insight into general topics that respondents find important, they do not allow respondents to elaborate upon these issues or bring up thoughts outside of what is presented to them. Interviews give respondents the most freedom to voice their own opinions. When interviewees discuss a topic not previously considered by the interviewer, they broaden the range of data. With time and space to speak about these topics, the interviewees offer more nuanced and detailed data.

To conduct qualitative research, investigators must be open and mindful of the data as it is collected. On the one hand, interviewers should allow the interviewees to guide the discussion by having them mention what they deem relevant. On the other hand, interviewers should use the content of interviewees' responses to ask follow-up questions and introduce related topics. With a qualitative method, researchers do not abandon structure in their study; they allow the data to structure their investigation. In doing so, they place value not only in the data itself but also in the dynamic process of gathering the data.¹⁷ Qualitative research is best employed when

researching the thought processes that underlie patient experience. As past studies on end-of-life care will reveal, this data encompasses patients' thoughts and expressions, whose full substance would not be elicited by questions with quantifiable answers.

To attain a concrete sense of patient priorities, Steinhauser et al conducted a cross-sectional, stratified random national survey of four groups of people: 340 seriously ill patients (defined as being hospitalized in the past year for advanced chronic disease), as well as 332 family members of patients who died in the previous 6-12 months, and 361 physicians, and 429 other care providers (nurses, chaplains, social workers, and hospice volunteers). They asked these people to rate on a 5-point scale the significance of 44 attributes of end-of-life experience, such as dying at home, absence of pain, talking about death, and spiritual concerns.¹⁸

These attributes were formed based on 12 focus groups and interviews with patients, family members, physicians, and other care providers, who were asked to discuss aspects of a good death. They began the discussion by telling people: "Today we want to talk about what constitutes a 'good death.' We are interested in finding out what you think would make a death good and what would make a death bad." Then, patients were asked questions like "What kind of things do you think would make a death a good death?" Follow-up questions, termed "probe" questions, inquired into specific aspects of dying, such as "How important would it be to have friends and family nearby?" and "How do you feel about being sedated?" These conversations enabled patients to speak openly about their feelings regarding death and dying. In the discussions, participants six general elements of a good death: pain and symptom management, control over decision making, preparation for death, a sense of completion in life, contributing to others, and being perceived as a "whole" person.¹⁹

Steinhauser et al incorporated these comments into the 44 attributes listed on their survey.

Among all groups, 26 attributes were rated important by 70% or more of the group. Five were related to physical well-being: absence of pain, absence of anxiety, absence of shortness of breath, being clean, and having physical touch. Four attributes involved preparation for death: feeling prepared to die, feeling that one's family is prepared for one's death, having expectations concerning one's physical condition, and completing financial issues. Three attributes dealt with attaining a sense of completion in one's life: saying goodbye, attending to unresolved matters, and reflecting on personal achievements. Two attributes concern decision-making: documenting treatment preferences and naming a person to make decisions if one could not. Seven attributes comprise what focus group participants defined as "being treated as a whole person": dignity, sense of humor, presence of friends, not dying alone, having people to listen, and having a physician who views patients holistically. Five attributes are related to the patient-provider relationship: having care from one's personal doctor, trusting one's doctor, having a doctor who can discuss end-of-life issues, having a doctor with whom one can speak to about personal feelings, and having a nurse with whom one is comfortable.¹⁸

There were several attributes that 70% or more of patients considered important that physicians did not rank as important: mental awareness, funeral arrangements, helping others, not being a burden to their family, friends and society, coming to peace with God, and prayer.¹⁹ In light of these factors, it is important for providers to be aware of patient needs beyond physical comfort. Also, providers may be inclined to focus on what patients need and overlook what they would like to give; this study shows that patients are concerned with helping others and ensuring the well-being of their loved ones. On the other hand, some attributes received more attention than perhaps was warranted. For example, compared to patients, providers were more likely to rank talking about death and personal fears as important.

This study provides insight into which circumstances patients find most ideal for their deaths, and offer general categories (physical well-being, preparation for death, sense of completion, decision-making, and patient-provider relationship) for care providers to address. It also highlights what providers may overlook in their assessment of what is important to patients, and gives an idea of what to emphasize in end-of-life care. However, the survey method significantly excludes patient perspective by 1) presenting respondents with pre-defined categories rather than eliciting the categories from respondents themselves, and 2) lacking opportunities for patients to expand on what the attributes meant to them, and why they rated them in a particular way. Because the survey's content is based on previous interviews with patients, the subsequent respondents are limited to the issues that a select group has raised. It is therefore necessary to build upon the general information gathered in this survey by seeking in-depth discussion with patients.

Qualitative studies designed to incorporate more patient voice did so in a variety of ways. Singer, Martin, and Merrijoy conducted discussions to address particular questions regarding end-of-life-care.²⁰ They spoke to three patient groups: dialysis patients, HIV patients, and residents of a long-term care facility. With each of these groups, Singer et al asked about specific areas of their experience. For example, they examined patient control at end-of-life among long-term care residents by asking them the following questions: “(1) had they previously thought about it? (2) what were their general views on control over decision making at the end of life? (3) what would be their personal preference “when the time comes”? (4) did they see any potential obstacles to having their wishes honored? and (5) what were their personal views about withdrawal or termination of treatment, as well as euthanasia and physician-assisted suicide?” Through such questions, Singer et al aimed to frame the discussion in terms defined by patients

instead of by experts in end-of-life care. For example, instead of speaking about a broad, somewhat ambiguous topic like “quality of life,” patients can identify more specific aspects of care. Moreover, interviewing patients shifts the focus from components of end-of-life care from things that are measurable to things that are most important to patients, even if they are not quantifiable. Their responses were categorized into five domains of quality end-of-life care: having sufficient pain and symptom control, not unnecessarily prolonging the dying process, attaining a feeling of control, easing burden, and strengthen connections to friends and family.²⁰ This interaction with patients and direct inquiry into their thoughts and preferences offer a wealth of information about patient perspective at end-of-life. As conversations, interviews can explore in detail the point of view of patients regarding certain parts of end-of-life experience.

Such discussions are both informed and limited by the fact that they address pre-formed, specific questions (What do you think makes a good death? What are your views on personal control in decision-making?). Going into interviews with the intent of asking such questions ensures that information related to these particular topics is obtained. However, it may also prevent patients from introducing their own topics of concern, which may lie outside the realm of the investigators’ original interests. As such, these studies are sufficient in answering certain questions about end-of-life care, but may overlook other issues that are significant to patients. The results from these studies reveal broad categories of concerns considered important by patients. This is extremely helpful in identifying specific items for care providers to address with their patients. But to broaden our understanding of patient needs, it is useful to learn more about aspects of patients’ overall experience not specifically examined in these studies. Feeling that previous work focused on creating universal models that would assist physicians recognize general themes in end-of-life care without truly exploring the range of patient experience,

Yedidia and MacGregor emphasized eliciting patient narrative in their investigation. In their study, they asked patients to speak about “what it feels like to be seriously ill, what provides strength, what is meaningful, what is difficult, how they view the future, and how they perceive death.”¹³ Because they did not guide patients to discuss specific parts of their end-of-life phase, Yedidia and MacGregor let patients choose what was most important to them to mention. This method allowed patients to construct their own means of telling their stories, and choosing what to share. As a result, this study gathered information on how individuals approached death as an entire experience. Instead of finding commonalities among all respondents to propose a general model of the dying process, it presents different ways patients cope with dying.

Based on these interviews, Yedidia and MacGregor formed seven motifs to describe varying perspectives on death, which they defined as: struggle (living and dying are difficult), dissonance (dying is not living), endurance (triumph of inner strength), coping (finding a new balance), incorporation (belief system accommodates death), quest (seeking meaning in death), and volatile (unresolved and unresigned). The struggle motif encompassed the idea that life had always been difficult, and dying was a continued part of the difficulty. The dissonance motif compared a past life with dying, where patients could no longer be who they used to be; patients thus saw dying as “the end of their story.” The endurance motif placed value in maintaining strength and optimism during times of difficulty. For patients showing the incorporation motif, dying was part of an overall belief system that may be but is not necessarily religious, and as such did not require particular change to deal with it. In contrast, the coping motif prevailed on adjustment to the experience of dying. People with this perspective want to restore balance in their lives, counteracting the negatives of dying with new or past means of positive support. People believing in the quest motif perceived in dying the chance to grow and to discover as

much as they did in living. Death, then, was a continuation of the exploration and possibilities of life. People with the volatile belief, on the other hand, did not possess such a cohesive direction. They suffered from an accumulation of difficult experiences, of which dying was another one, that remained unresolved.¹³

These studies on patients' perspectives at end-of-life have nicely explored patients' thoughts and opinions on death. Steinhauer et al examined how patients defined a "good death," or their preferences for how the actual act of dying would occur. Similarly, Singer, Martin, and Merrijoy investigated what patients most wanted at the time of their deaths, from their symptom management to end-of-life measures to relationships with loved ones. Yedidia and MacGregor expanded the scope of discussion by asking patients what it was like for patients to be terminally ill; however, their interpretation of the patient conversations focused largely on how patients perceived death itself.

In our study, we are interested in how the rest of patients' lives are informed by the broader context of being terminally ill. While we continue to investigate patients' perceptions of death, we also want to know how patients live day to day. Like Yedidia and MacGregor whose method of interviewing allowed patients to form their own stories, we adopted a similarly open-ended method. In contrast to Yedidia and MacGregor, we did not ask patients to speak about specific topics such as "what provides strength, what is meaningful, what is difficult, how they view the future, and how they perceive death." Although these topics are general enough to elicit open patient narrative, they still focus on specific areas of this phase of life (difficulties, sources of strength, and so on), which assumes that these are what patients most want to discuss. Instead, we simply asked patients to speak about what it has been like for them during this period in their lives. They can thus choose for themselves what is most significant to share. As a result,

patients spoke not just about their views on death, as elaborated by Yedidia and MacGregor, but also on life. What do patients want to accomplish each day? What do they think about upon waking up and upon performing their daily routine? What is their daily routine? What motivates their actions, in regards to the treatment of their illness as well as other aspects of their lives? What has been most important to them not just in this end-of-life period, but in their entire lives? As medicine becomes increasingly distant from the patients it seeks to treat, these conversations bring us closer to the source and destination of our care—the patients.

Statement of Purpose

With the goal of better understanding terminally ill patients' thoughts and concerns at end of life, this study uses qualitative methods to interview patients. In doing so, we aim to:

- 1) Attain a more comprehensive, in-depth understanding of the issues most important to terminally ill patients during their end of life care;
- 2) Enable patients to guide discussions of what their lives are like while they are ill;
- 3) Record how patients describe their experiences in their own words;
- 4) Offer information to care providers on how to approach discussion with patients regarding their experiences during end of life

Methods

To pursue the aims of this research, we designed a qualitative study using interviews with terminally ill patients who were receiving care at clinical sites within the Yale community. We first recruited patients for interviews, as described in the following section on data collection. The structure of the interview is explained in the section on design. After interviews were conducted, the transcripts were read and reviewed to identify categories of discussion. These categories were then examined further for recurring themes, within each category and among categories. This process is described in the analysis section.

Data collection

Patients were recruited for the study through healthcare providers who care for terminally ill patients, including the hospice unit and ALS clinic at the VA hospital, the Yale oncology clinic, and the geriatrician working on this study. In the beginning, the majority of the initial patients were older (70 years and above). When the investigators felt that information from these interviews constituted data saturation, they sought to recruit patients from a different demographic age group (younger than 70 years). In some cases, patients were seen for follow-up interviews. Typically these occurred if the patient's health situation changed or if the patient was faced with a new decision. This longitudinal follow-up enabled us to follow the course of the patients' experiences. Given the personal nature of the interviews, most were conducted with only the patient, rather than in groups of patients.

Fifteen patients were interviewed for one or more sessions for a total of 20 interviews. . Four patients had a family member present for the interview, per the wishes of the patient. All but one interview was performed in person with KTN, either in a clinical setting or the patient's

home. One interview was performed by phone at the request of the interviewee. The interviews lasted between 30-90 minutes. They were all recorded and transcribed. Two individuals (KTN and MAD) analyzed the interviews as they were transcribed, coding the interviews for themes. This continual analysis guided the sampling process, in determining the number and type of patients to interview and the saturation of data.

Design

After choosing the qualitative method of interviews, the design of the study focused on how the interviews would proceed. When patients were asked to participate, they were read a prompt summarizing the purpose of the study. This same prompt was used to begin the interview (Appendix A). To ensure as much comfort as possible in discussing sensitive issues, interviewees were told that they could pause or end the interview at any time. They were assured that interview content was confidential, and that both the recording and transcript of the interview would be made available to them if desired.

To enable interviewees to most freely discuss what they had on their minds and to keep within their comfort levels, the interviewer did not use a pre-defined list of questions. Based on information provided by the interviewee, the interviewer developed prompts to further discussion. There are two general types of prompts: floating and planned. Whereas floating prompts are formed during the interview, planned prompts are designed ahead of time. In this study, planned prompts were developed as recurring themes emerged in the interviews. For example, after several patients mentioned how seeing another person experience dying affected their own perspective, the interviewer developed the following planned prompt in response to any patient mentioning having witnessed another person face death: “How did that experience

influence how you approach your own situation?” In this way, qualitative research is a dynamic process, where information collected may guide the investigation as it progresses.

Analysis

As mentioned, a key component of qualitative analysis is the ability to begin analysis as data is being collected, helping to guide the progressing data collection. This enables the investigators to improve interview methods and consider recurring themes that may shape interview prompts. It also allows the investigators to develop and change hypotheses as the data are collected, thereby giving more weight to the interviewees' responses than to the investigators' initial impressions. In this way, researchers use an inductive process of analysis: they examine the data to identify analytical categories used to describe and explain human behavior and thought. This approach was defined as “grounded theory,” where hypotheses are developed as research progresses rather than from the outset.²⁰

To characterize and set guidelines for this process, the “framework approach” was developed. We employed this approach in our study, which includes five stages: familiarization, identifying a thematic framework, indexing, charting, and mapping and interpretation.^{21, 22} As the first stage, familiarization encompasses the first encounter with raw data, which in our study included the interviews and the transcripts of the interviews. In this phase, the researchers get to know the content of their data and may begin considering how to categorize recurring themes. By first conducting the interviews, and then reviewing them thoroughly several times in transcript form, the researchers are able to build upon their initial acquaintance with the data, absorbing details and patterns that may have been missed during the data collection.

In the second stage of the framework approach (identifying a thematic framework),

researchers consider general categories and issues that have been observed in the raw data. These are identified after the researchers have undergone enough familiarization with the data to recognize recurring topics within and among interviews. These topics can be called categories, and the raw data can be then be coded by category. In our study, we developed fifteen categories: quality of life, course of illness, approaches to treatment, personal goals, hopes, fears and worries, decisions of daily living, place of living, family, prior experiences with death and dying, religion, timeframes, memories, attitude and emotion toward dying, and adjustment. These categories were formed by KTN and MAD after five interviews were conducted, transcribed, and reviewed. KTN and MAD independently made a list of categories based on these initial interviews. The final list included categories that both researchers identified, as well as any categories that one researcher identified that was not identified by the other. This made it less likely that a significant category would be excluded. The interview content that contributed to forming these categories is presented in the *results* section. As such, the *results* represent the initial stages of the framework approach: familiarization and indentifying frameworks.

Once categories are established, researchers enter the third stage of *indexing*, where the raw data is coded by the categories.²¹ This is done using the software NVivo7, and the method is described by NVivo as topic coding, where “topic coding is the process of assigning references within your data to the topics, categories or concepts they relate to.”²³ This entails reading the transcripts of the interviews, and identifying any content related to the categories established in the previous stage. Once the researcher identifies this content, NVivo allows the researcher to “code” the content by the category. Later, the researcher can view a particular category and see all of the interview content that has been coded under that category. For example, if a patient mentions spending time with her son, the researcher can highlight this content in the transcript

and code it under the category “family.” After all the interviews have been coded, the researcher can look under the category “family,” and see what content in all of the interviews have been coded as relating to “family.”

In our study, two separate researchers (KTN and MAD) independently coded the transcripts using the categories previously described. Again, this was to ensure that as much content was identified and categorized as possible. Because these categories were formed gradually as interviews progressed, several categories were added as interviews progressed. Interviews that had been coded before the new categories were added were re-coded to include these categories.

After data is indexed by category, the qualitative data then undergo *charting*. In this stage, researchers examine the data coded by category and rearrange the data based on other observed patterns. The data coded under certain categories could be further divided into subcategories by characteristics of the respondents.²¹ For example, in this study, data coded under the category “attitude and emotion toward dying” could have been further divided by patient age. It would be possible to divide the patients into groups older and younger than 65, and compare the content of “attitude and emotion toward dying” between these subcategories. However, we did not pursue further charting in our study. Although individual responses displayed variety and differences, each category contained several recurring ideas. We found that analyzing the same ideas among patients with very different characteristics provided greater insight into patient thought than grouping patients into different categories. For instance, there were themes in the category “attitude and emotion toward dying” that the majority of patients discussed, regardless of age, and this gave more information about how to approach patients at end-of-life than examining the more minor and obvious differences between patients of different

ages.

The final stage consists of *mapping and interpretation*, where researchers study the charted categories for themes within and among the categories that describe the human behavior and thought that they are investigating.²¹ In our study we examined patient responses within one category for similarities and contrasts in how patients discussed the category, and formulated themes based on patient responses. This mapping and interpretation was initially conducted independently by both KTN and MAD. Each researcher described themes identified by reviewing the content of each category. We then met to discuss our individual findings, and KTN consolidated the separate interpretations. Once we identified themes within the categories, we looked together at the data broadly to determine if there were associations between the themes in different categories. The interview content that contributed to identifying these themes is presented in the *discussion* section. As such, the *discussion* represents final stage of the framework approach: the mapping and interpretation.

Results

The patients interviewed represented a variety of demographic attributes, which are shown below.

Attribute Category	Specific Attribute	n
Gender	Male	9
	Female	6
Age	≥65	10
	<65	5
Illness	Cancer	7
	Heart disease	4
	ALS	2
	Other	2

As the specific circumstances and histories of the patients may inform the content of their interviews, it is important to understand the backgrounds of the interviewed patients. These descriptions are based on the patient at the time of the interview.

EA: 29 year old man with Hodgkin's lymphoma who was pursuing palliative chemotherapy. He enjoyed working on automobiles and attending car shows. He had an 11 year old daughter with whom he is very close.

EM: 93 year old woman with chronic renal failure. She knew that her renal function was steadily declining, but was unsure as to when this lead to passing away. She had been a nurse until she married and had three sons, after which she dedicated her time to taking care of them. Her hobbies included painting and reading mystery novels.

EP: 93 year old woman with nasal melanoma. She had been a librarian, and loved to travel. No longer able to travel, she enjoyed reading about other places. She was a widow living alone; she had a daughter from Massachusetts who visited frequently, and a son in California.

FS: 58 year old man with stage four breast cancer. He had worked as a research scientist in a hospital-based epidemiology research center until he became sick. Since then, he had devoted his time to writing nonfiction, and was currently working on a collection of essays. He lived with his wife, his primary caretaker.

GJ: 64 year old man with amyotrophic lateral sclerosis, diagnosed eight years ago. He was wheelchair-bound, and beginning to lose his voice. He had been a truck driver for an oil company. He lived with his wife, who quit her job to take care of him.

HH: 88 year old woman with lymphoma. Her husband had been a minister and divinity school professor, and had passed away from Parkinson's disease several years earlier. She had three children, one of whom depended largely on her financial support.

JA: 67 year old man with esophageal cancer who came to the West Haven Veteran Affairs' Hospital from Puerto Rico. He was admitted to the hospice unit at the VA. He was a devout Catholic who had four daughters.

JB: 75 year old man with amyotrophic lateral sclerosis, with symptoms beginning three years ago. He was walking with a cane. He had been an anesthesiologist. He lived with his younger wife, whose welfare was one of his major concerns.

JM: 64 year old woman with lung cancer metastatic to her brain. She was at a rehabilitation center, and her daughter was an advanced practitioner nurse in hospice care.

JP: A 63 year old man with congestive heart disease. He was a veteran whose last job before becoming ill was performing maintenance at the Christmas Tree Shop, a convenience store. He lived with his wife and was mostly bedridden.

MG: 89 year old woman with bronchoalveolar lung cancer that had been diagnosed six years ago. She had chosen not to pursue further investigation and treatment until it recently metastasized to her bones. She initially chose to then pursue non-chemo medical therapy, but later ceased treatment. Her son from California came to live with her during this time.

RL: 87 year old man with lung disease and heart failure. He was living at home with his wife during his first interview, and was interviewed again when he was admitted to Connecticut Hospice.

RW: 65 year old man with congestive heart failure who had been admitted to the hospice unit at the West Haven Veterans Affairs' Hospital, but had improved and was hoping to transition to a retirement home setting. He served in the army and was stationed at the Dominican Republic. He was a Jehovah's Witness.

VM: 97 year old woman with coronary artery disease and end stage aortic regurgitation. She began receiving home hospice after she was admitted to the health center in her retirement community for a heart attack. She required oxygen at home, where she lived by herself.

WC: 66 year old man with lung disease and recurrent pneumonias, who was admitted to the hospice unit of the West Haven Veterans Affairs' Hospital, where he had decided to stay until passing. Feeling that his passing was imminent, he was focused on getting his affairs in order.

In speaking about their experiences, these diverse patients bring up a number of topics. These topics were identified by KTN and MAD, and are presented here with the content used to identify them. They include the following: quality of life, course of illness, approaches to treatment, personal goals, hopes, fears and worries, decisions of daily living, place of living, family, prior experiences with death and dying, religion, timeframes, memories, attitude and emotion toward dying, and adjustment. The number of quotes selected to represent these categories are indicative of how much overall content was included in the category. For example, the category quality of life contained six pages of quotes, while the category course of illness contained two. The quantity of quotes for the respective categories reflects this difference in quantity of overall content.

Interview content is presented in both the *results* and *discussion* sections. The interview content presented here represents the information that helped the researchers identify the 15 categories. That is, they provide evidence that these topics were discussed by patients. As noted in the *methods* section, this encompasses the initial stages of the framework approach: the *familiarization* with the raw data, and then *identifying frameworks* by forming categories.

Quality of Life

Patients speak at length about what it is like to live with the effects of their illness. This includes pain, sleep, appetite, mobility, and relationships, among other things.

EA: I lost a lot of weight 'cause of loss of appetite; I just didn't want to eat. I'd try to eat and then it would come back up....it tends to hurt after coming back up so much and for the last three years I've been on pain meds.

FS: The only problem I had in terms of living of course is pain...and I'm on crutches, you know, I can't work anymore.

GJ: When my lung capacity is at 34% I really can't hold a conversation without trying to breathe hard, and that's frustrating to me. The most is my ability to speak and that's rough on me.

GJ: That bothers me. I can't hold [my grandkids].

JM: You know, I couldn't get my breath. I'd go up and down stairs and it was an effort. Then I went to the chemo with the taxol. It affected my feet, so I have trouble walking....I had to use the walker....I had trouble using the commode.

VM: I had that nauseous feeling all the time and it's really awful....I try to do things in the kitchen—forget it.

Course of Illness

When speaking about their experiences as patients, several people summarize the trajectory of their illness from initial diagnosis through progression of disease and treatment.

FS: I was taking a shower in a stand-up shower stall...I started to soap myself up, you know; I felt a big lump there. So then I was more concerned, looked in the mirror afterward, and then I saw my private care physician....He thought it was a solid mass that would resolve. But he ended up checking things further and we were in contact with...the breast surgeon at Yale....they did a biopsy and whatnot. She confirmed the diagnosis and she did my mastectomy....So then Dr. Chung had me have a series of radiation.

EA: I have terminal cancer. It started off in my colon, I want to say about three years ago, spread to my liver. They have found some spots in my lungs.

GJ: There are a lot of different stages. A lot of different progressions throughout the illness, you know, from walking, using a walker, to falling, then to using a wheelchair. You know, I was able to put my hand on the toggle switch; now I can't do that.

Approaches to Treatment

In their *descriptions* of illness, interviewees discuss their treatment and their philosophies underlying their choice of treatment.

HH: I don't want the children to have to take me out and shoot me. I think it's about time to turn loose life, this life at least. I'm not a strong believer in an afterlife, but I'm not gonna push for every little thing to be done.

MG: Just in general, I just don't think it's wise to prolong old people's lives.

EA: The big thing a lot of people want to know about is side effects, how it's going to affect you.

FS: Now my philosophy is let's do the maximum treatment. Don't worry about the pain. Don't worry about the side effects. You know, I'll handle it one way or the other.

As seen here, people have different approaches to their treatment. In part, this has to do with the goals people set up for themselves in terms of functioning.

HH: If the rest of me, like my mind, is not alright, I'd rather just see what happens if you let the lymphoma do what it wants to do.

FS: I don't want to be bedridden completely.

JB: I will accept that, you know, I'd be in a wheelchair and I can't walk. And now, if I couldn't move my arms and I couldn't move my legs and had to lie flat, I think that might be an end point.

Approaches to treatment are often guided by people's goals for other aspects of their lives, which is a topic of discussion for a number of interviewees.

Personal Goals

Interviewees often mention things they wanted to accomplish before passing, from completing a creative product to ensuring that their family members were financially stable. They also have goals for their quality of life, such as maintaining mobility or having control over their bodies. Other goals are related to battling their illnesses as best they could.

FS: My goal is to keep mobile for as long as possible and not be bedridden....The other goal is just to become mobile so we can enjoy ourselves. We went out the other night and found a little restaurant.

MG: I just thought I wanted my body back.

JM: I'm willing to try anything...To function. Like a human. Being a little more independent. I'd like to be able to get up and dressed and walk.

HH: I would like time to go get ready and get things in order.

Some goals are related to helping others, not only loved ones but also strangers.

EA: As long as I can help somebody else out that might be going through it and I can answer some questions that they might have, that's a help to me, you know?

RW: I'd like to do something with my life. Help people, you know?

Hopes

Related to goals, which people have a certain sense of control over, are hopes, which are things people wish to happen and cannot necessarily control. MG hopes to live long enough to see her great-grandchild born. GJ hopes to simply live “a little while longer.” Some interviewees hope to leave behind specific messages and perceptions of themselves:

HH: I would like to be perceived as a person who was not selfish and who was kind to her friends. That’s about it.

EA: I just want people to remember the good times and remember you gotta keep fighting, you can’t give up.

Interviewees all hope to have enough time remaining to achieve their personal goals.

Fears and Worries

People sometimes feel that they will not be able to achieve these goals, and that concern comprises much of people’s worries. People also have fears regarding how they will die.

HH: I hope I won’t have to die in the hospital.

VM: I don’t want to suffer.

EM: I just don’t want anything dragged out.

The uncertainty surrounding these circumstances, and how disease will progress, contributes to the fear and worry people harbor, as EP mentions when she says “I don’t know what it’s going to be like.”

Decisions of Daily Living

While interviewees speak about their thoughts on illness in general, much of their conversation centers on their daily life. On the one hand, patients recognize the limitations that their conditions impose on their lives, and plan their lives accordingly:

HH: At the time I faced the lymphoma, I also faced that fact that I could not do things that were too complicated and difficult and where I needed a lot of rest.

MG: I was vice president of the council...and they just had an election, and I was afraid they were gonna make me president and I just resigned. Well, I went to the meeting and I talked to the leading president and I said I really can't, I don't know, my future's too uncertain. So I just resigned.

The prospect of death also necessitates decisions regarding funeral arrangements, financial situations, and day to day choices such as whether it's worth buying a new bathing suit:

FS: We have to handle the income first, so [we] have to plan how we're going to exist financially.

WC: I had my daughter and my wife go to the funeral parlor and set up funeral arrangements.

MG: I think of the humorous things too, like...I need a new bathing suit, but I do really want to spend that much money?...I think well you know, I don't really need that.

Place of Living

One aspect of living where patients express strong choice concerns where they live. RW would like to move to "retirement place," where he can be somewhat independent. He is adamant about not wanting to be in a rest home, where people have to look after him:

I don't think I'm ready for a rest home yet. I'm too self-sufficient I think for a rest home. I want to go into like a retirement place...cause I can always get someone in to do my housework if I have to. The rest home don't really care if you get out of bed or not, you know?

RL expresses distaste for nursing homes and hospitals, and prefers to stay at home:

I'm very comfortable when I'm at home....My wife cooks and I like it. I have a huge television, a 46 inch. So that helps. I don't see too well....I don't want to go back to the hospital and I don't want to go back to the nursing home....get me home and leave me there.

Most often patients have the desire to remain wherever they have been living, whether it be a house or retirement home.

Where people want to live is often related to where people want to die. As seen in the topic of fears and worries, some patients like HH express a desire to not die in the hospital. GJ notes that he wants "to die at home."

Family

Interviewees speak about their families in a variety of contexts. Frequently, patients

mention the change that one person's illness has caused in the familial relationship. Related to quality of life, people want to spend time with their family, and family provides a source of support for them:

HH: I try to stay in touch with the children and the two younger children stay in touch with me.

MG: My son's come here from California to be with me and of course it's an enormous help.

RW: My daughter comes and sees me, my sisters, my nieces, my grandchildren. If they didn't come to see me, I think I'd be lost.

However, there is concern over being a burden to family members, and having to be taken care of by others.

GJ: I'm not easy to live with in respect of not be able to do anything for myself. Eating. Water. Bathroom. Wipe my eyes. You know, so it takes a toll on [my wife] as well as me.

HH: I really don't want my son Peter...to be burdened so long with having "got to go see Mom, got to take the boys to see Mom."

In addition to being cared for by family, patients emphasize the need to take care of their families, and ensure that their futures are stable once patients pass. For people like GJ, JB, FS and RL, this is primarily focused on their wives. Others like HH mention her children.

Prior Experiences with Death and Dying

When patients have seen family members or others pass away, they draw upon these experiences to formulate thoughts on their own circumstances. People who were care providers by profession, such as EM who was a nurse and JB who was an anesthesiologist, have seen patients undergo life-preserving measures. As a result they seek to avoid the same situations. Others who took care of family members over a long period of time, like HH whose husband had Parkinson's, recognize when illness had deprived him of quality of life: "He couldn't do anything. So I really, I felt I couldn't grieve for him too much because he just would not want to go on living that way." MG had a similar experience with her husband: He wasn't the man I

married. He was different, and I don't think he would have wanted to go on." Both HH and MG endorse not wanting to continue after losing a certain degree of awareness and ability, and refer to having seen what it was like for their spouses. GJ felt likewise about his mother: "She knew it was her time and she didn't want to be kept alive by a machine, because that's no quality of life."

Religion

Interviewees refer to their religion or absence of religion, often by way of referring to the support a religious community or belief offers them.

FS: I've very active in our church for the most part. So, the camaraderie that I find in church, we have a lot of good friends there, that makes living worthwhile. That's very important to us, very important to me.

For EA and JA, the idea of God gives them comfort, with EA believing that his illness is part of God's "calling" for him, and JA and WC feeling that someone is "watching" them.

WC: I believe He's up there. I believe He's still watchin' over everybody. I believe He's watchin' over me. I talk with my pastor every four or five days and say prayers. I believe in Him and I believe what He stands for and what He says.

Others refer to the afterlife when discussing the notion of death. WC feels that he will live forever, whereas FS feels that because there is no afterlife there is no uncertainty about what happens after death.

Timeframes

When faced with the prospect of death, time becomes a subject of concern. In this way, people talk about the progression of their lives in terms of their illness and the time it allows them. FS mentions that terminal illness colors the way he thinks about the amount of time he has remaining: "One does think about what's gonna happen. How long are you going to have?" Because there is limited time remaining, people now make deadlines, both specific and vague,

for completing their personal goals. People like EM, HH, and FS invest in creative works they want to finish before dying.

People often perceive older age as a timeframe for dying, and so older patients recognize that they are at the age for death:

HH: I've lived longer than my husband. We were the same age and I've lived already two years—he was 86—two years longer than he, three years longer than my mother, and 20-odd years longer than my mother. I've had more than my share of life's good things.

VM: I knew that my time was short....I never expected to live so long.

Memories

In thinking about the end of their lives, interviewees bring up their past, both pleasant and meaningful memories and reflections on regrets. People speak about travels, family, and work:

EP: I enjoy, you know, thinking of those places I went to. Once I took a trip on the Trans-Siberian Railroad. That was, as I said, 1986. And that's the biggest trip I ever took....ever since I was a little girl I've been fascinated with the Trans-Siberian Railroad.

HH: Traveling has been extremely important to me. I've always wanted to travel and so I've planned the trips and I've financed them I might say, from my own funds.

EM: When I got married, I stopped work because my husband was a fireman and it was hard work for him....And there were—we got three sons....So I decided I needed to be there to take care of the house and meals and things. So I haven't worked since.

JM: I'm chairman of the police commission in town. And I built the transfer station in Branford....I built that back in the 80s.

People also mention less pleasant moments in their lives. For HH this includes the end of her husband's life and the difficulties he faced, as well as caring for a troubled son. RW discusses the life-changing event of losing his leg and not being able to work.

Attitude and Emotion Toward Dying

In speaking about concrete aspects of being ill, patients also mention how they feel about the experience and the prospect of dying. Some interviewees express sadness and anger over the negative elements of illness: inactivity, effects on relationships with loved ones, uncertainty of

how things will progress, a feeling of helplessness. FS and GJ are upset that they cannot be as active as they once were, as FS says: “I get angry in a way that cancer is preventing me from doing things.” RW is sad to miss seeing his “grandson and granddaughter growing up.” GJ cries as he talks about his illness and the inability to do anything about it:

Never sick a day in my life...Always healthy...it’s hard talking about (*sobbing*)...And nobody can help. There’s no medicine or nothing out there....If it was something lifestyle, you know, that I did, whether it’s smoking or my job, I would maybe get out of what I was doing. But I don’t know why this happened and I can’t change what is.

On the other hand, the same interviewees and others emphasize positivity in thinking about their situations. People like MG focus on “thankfulness” for the time they have had. Others like EA endorse the need to “keep thinking positive.”

EA: You got to have something in life that you look up to, like I have my daughter and I look up to her and I do a lot because of her and then I have a car that was built for me. They built a car for me and that makes me think positive and gives you some hopeful thing to go through this stuff.”

In this way, people express a range of emotion and attitude toward dying.

Adjustment

When discussing the experience of being ill, people speak of things that make the process easier on them. Their attitude toward dying is a part of this adjustment. Though they do not always speak of these things directly as “adjustment,” they note that certain ways of thinking or doing things have helped them cope with their situations. These include receiving and giving support, finding ways to be active within their limitations, focusing on gains rather than losses, and acceptance of their circumstances.

EP: I’ve had a good life. Very good. I’ve got a wonderful family. I just think how fortunate I am to be as good as I am for as long as I can be....I’m sort of resigned to [dying], you know. I’m not afraid of dying. I figure I’m going to do it, so.

JP: I don’t like it, but I mean it’s a part of life. That’s a part of life you gotta deal with.

WC: Life is full of good and bad. We just take it as it comes.

MG: [My doctor] put me on physical therapy, which I am very grateful for because it gave me something positive to do to strengthen my right leg.

It is this process of adjustment—how patients process their illness and experience it—that connects all these categories describing patients' thoughts at end of life.

Discussion

When trying to understand patient concerns at end of life, we often think of death and dying. This limited perspective may obscure certain aspects of patient experiences which are related less to dying than to living within a different framework. Some of these elements were elucidated in our study when patients were given the opportunity to speak freely and choose their own topics of discussion. As evidenced by the categories identified from these interviews, patients raised a variety of topics. Within each of these topics there are different themes characterizing patients' thoughts and emotions, which will be discussed in turn. Before doing so, it is important to examine the common lens through which patients consider these seemingly disparate issues.

Once patients face a life-threatening illness, they acquire another frame of reference with which to view themselves and their lives. While few patients explicitly describe this experience in terms of discrete stages, their thoughts during our interviews revealed a process with several parts. Patients first confront the idea of change: that their lives will be different from what they have known previously (though there is great range in the severity of this change for patients, change is evident for most). Patients often express disappointment in not being able to function in the same way, and these functions are very much related to their identities. As such, with illness comes a loss of self-identity.

As patients grapple with these changes and sometimes undergo a certain deconstruction of the people they had perceived themselves to be, they then strive to rebuild their self-identities. Within the constraints of their illness, they find means to continue embodying what they see as their defining characteristics. In some ways, illness gives patients another venue to demonstrate qualities and principles important to them.

Even as patients attempt to retain their former selves through their illness, they acknowledge that their lives will not be fully restored to what they were and that their identities need new avenues of expression. In speaking to patients about their experiences, it becomes clear that illness is a fundamental change to a patient's life. This challenges each patient to maintain the same sense of self in a different form. These experiences will be explored further within the individual categories of patient concerns.

Interview content is presented in both the *results* and *discussion* sections. The interview content presented here in the *discussion* represents the information that the researchers used to identify themes within and among the 15 categories established in the *results*. As noted in the *methods* section, this encompasses the final stage of the framework approach: the *mapping and interpretation*. Whereas the interview content presented in the *results* provide evidence that patients discussed specific topics, the interview content presented in the *discussion* show evidence for the development of themes regarding these topics. For example, in the *results* section, the quotes in the category "family" show that patients mentioned the importance of their families during interviews. This contributed to the researchers' identification of "family" as a category, which is part of familiarization with the raw data and identifying a framework. In the *discussion* section, the quotes in the category "family" will provide evidence for the theme of how family is connected to a patient's sense of self, which is part of mapping and interpretation. Below we present the themes identified within each category, and the interview content on which the themes were based.

Quality of Life

When considering patients' quality of life during their illness, a recurring topic of

discussion is their autonomy in conducting their normal lives. This has a great deal to do with their physical activity. They often refer to their level of activity before they were sick:

EA: The thing that really stinks about this whole situation is I was a very active person before all this. I was always on the go and this and that, and now it just slows you down and you really can't do a lot.

RW: I was a really active person. I always kept busy.

HH: I've gradually gotten less and less independent....Life is extremely limited now of course. I can't go anywhere.

EP: You know, I used to play tennis and things like that. I can't go as many places as I used to like to go to. I used to like to travel. If I didn't have all of this going on, I certainly wouldn't just be sitting around here doing nothing.

Wife of GJ: [He] feels helpless. He was very very active and he did all the yard work and he did all the maintenance of the property, and now it's very difficult for him to depend on others to do this stuff.

For most patients, illness decreases their baseline level of activity and thereby disrupts the things that they feel define them and that give them individual agency. For one patient with ALS, the most difficult change has been to lose his ability to speak. Similar to this physical change, patients metaphorically lose their voice when they can no longer choose to do the things that they feel are part of who they are.

Patients express different approaches toward this change. Some, like EP, accept the differences: "I have bad health and I can't do everything I'd like to do." It is important to note that although EP endorses accepting the loss of things that had been previously important to her, she speaks of her acceptance as part of her character: "I don't really get into a swidget over things. If I can't do something, I just accept it." Even though she may have lost some of self-defining abilities, she deals with this loss by maintaining the rest of her character.

Others deal with the decrease in their activity by seeking ways to continue to be as active as possible. Although people lament their current situations compared to how active they were

before their illness, they also value any progress compared to the lowest point in their illness.

Within their limitations, patients try to continue their previous lives to a lesser degree:

JP: When I came home...I couldn't move around. I couldn't do nothin'. I can get up out of this bed now...I can get up and sit on the side of the bed and take my reacher and reach and pull stuff. And you learn how to do things when you, you know, you get into certain conditions....I can get the wheelchair and get the walker and transfer myself from the walker to the wheelchair. I couldn't do nothin' before.

RW: I'm here because I couldn't breathe anymore. I couldn't take ten steps unless I could sit down. But, I'm doing much better now. They changed my medications, so I'm taking breathing medicine and also oxygen, and I'm feeling a lot better.

HH: [My doctor] has given me permission to walk without an aide, which is a great liberator.

Even though patients cannot return to the same level of functioning prior to their illness, they are encouraged if they feel that they are actively working on their situation.

In this regard, physical therapy is a valuable means to maintaining a level of control.

Several patients mention the importance of physical therapy to them:

FS: Getting a physical therapist is not going to make or break the illness. It's still going to run its course, but it really contributes to increasing your quality of life. For example, I know how to go up and down stairs now.

MG: I had physical therapy...That was a big help. It was a positive thing to do and it was making my body stronger.

JB: I want to keep as limber as I can. Now my ankles are fixed all day as long as I have these [braces] on, you know. And when they're not on, I can move my legs forward and I can move my ankles. I can't move them actively, but I can do it passively. I want to preserve what I have, and that's what I'm doing with [my physical therapist].

For JB, the mindset that his physical therapist imparts is crucial to how he copes with his reduced abilities: "She said, 'We don't concentrate on what you've lost; we concentrate on what you have and what you can do with it.'" Having the mentality of remaining active, even if it is not to the same degree that patients previously experienced, maintains their sense of agency and thus sense of themselves. These seemingly minor movements can help patients cope with major changes in their lives.

Some patients also mention the importance of their mental faculty, especially as

their physical activity declines. For EP, her ability to read somewhat compensates for her inability to travel: “I like to read. It’s a good thing because I can’t do as much physically as I used to. If I can’t go places I can read about them.” Another patient, HH, feels that the primary thing she wishes to keep intact is her mental awareness. She notes that this is what allows her to find quality of life despite the limitations of her illness: “My mind is good enough yet to enjoy certain things. I went to the movies last Saturday.”

Interaction with people is another means for patients to maintain their sense of selves. HH and MG, residents at the same retirement community, both mention the desire to have meals with other residents. Relationships and regular social interaction are important to them. This is also true for patients who are in more isolated settings. For example, RL has had to stay in rehabilitation centers and hospitals, and he says that it is important for him to be situated in “general surroundings where people can visit and I can communicate with people.” Maintaining relationships established before patients become sick may help them retain a sense of who they are despite their illness.

When these relationships change, this can damage patients’ quality of life. GJ, a patient with ALS that has taken away his ability to move his arms and legs, became very emotional when speaking about how he can no longer interact with his grandchildren in the way he used to: “That bothers me. I can’t hold them.” Having strongly identified himself as an affectionate, playful grandfather, GJ is upset when his illness interferes with this role. Another relationship change that several interviewees mention occurs between patients and their significant others. That is, the balance of providing care shifts when one person in a couple becomes ill, and the other takes on tremendous responsibility in caring for the patient. While caregivers who were interviewed often

express that they do not perceive their significant others as a burden, the patients themselves are concerned with losing their independence and needing their significant others to take care of them. FS says his illness “produces a burden on the spouse...We’re here having this interview, but you know, I have to ask [my wife]: ‘Could you get my coffee’....Before I would walk down to the kitchen and get my own doggone coffee.” FS is unhappy that the responsibility of taking care of him affects his wife, from small inconveniences like this to larger obstacles like the inability to travel. When patients are in the position where others have to cater to their needs, they may feel that their relationships have changed and this may affect how they perceive themselves: as burdens rather than mutual partners.

Because quality of life is an important consideration for patients when making medical decisions, this discussion offers insight into how patients approach treatment of their illness. That is, when people consider quality of life, they are also thinking about how to maintain their identities.

Course of Illness

Perhaps because illness changes one’s perspective and life, the narrative of people’s illnesses are important to them. When asked to talk generally about their illness, some people begin with an extensive summary from initial diagnosis to present day, and offer specific dates for when events occurred:

HH: I moved down here [in the health center of the nursing home] the 26th of February....I was expecting to be down here about three days. I was in a large, wonderful apartment upstairs, but I never got back. And I’ve had one booster shot, two weeks ago...and I’m going to have one in, I think, late November.

EA: I’ve had cancer since I was 12 years old. I have Hodgkin’s disease lymphoma, so I went through chemotherapy when I was younger and then I went through some chemo before they did the embolization...they did that and I was done February 24th and March 24th.

For one family, FS and his wife, knowing the timing of a particular event—the placing of his skin grafts—seemed to be important. Neither person could quite remember the length of time during which FS could not lie on his back after receiving the skin grafts. FS and his wife discussed this for several minutes:

FS: I had skin grafts all over my back and I couldn't lay on my back on the tables for the biopsy. I couldn't lay on the table for about a month maybe?

Wife: I think it was a few months. It was like July maybe when that happened and it was maybe October or something.

FS: ...The metastases to the bone first recognized in June of 2008 – that was the injury that I had...It doesn't say when it was diagnosed.

Wife: But I think it was – you had the skin grafts in July I think.

FS : Well I was treated with Faslodex and everything – actually, I was treated before that. Anyway, it doesn't say when it was confirmed, but my recollection is it was about a month and a half. [My wife] thinks maybe two months or so.

Wife: I think it was longer because it took so long to even get the surgery on your back with the skin grafts and then –

FS: It may have been done before the skin grafts.

Wife: No. It couldn't be –

FS: No? You sure?

Wife: No, I'm sure. They were waiting to get the skin grafts done and heal, and so it seems to me it was about three or four months before you actually –

FS: I know it wasn't four months. I know that. It was somewhere between my recollection and hers. Hers is probably a little more accurate than mine.

Wife: I can remember how long it took because then you had the skin grafts, then you had to wait an unbelievable time for the skin grafts to heal. You know I put –

FS: He let me lie down on the table after the skin graft was given, the skin doctor.

Wife: Honey, I put lotion on your back for months and you had to wait to get the, I think it was the CAT scan of your back.

People may naturally want to feel a sense of control and possession of their narratives, which can become centered around illness when they face a terminal disease. This may explain why knowing whether the effects of a skin graft lasted two versus four months is so important to FS and his wife. When illness dictates so much of their lives, it becomes significant to feel that they have some control of their narrative by knowing the details and telling their story. This simple but often overlooked opportunity to narrate the course of one's illness may offer patients one means of maintaining their sense of self through a life- and identity-changing experience.

Approaches to Treatment

When patients speak about how they wish to treat their illness, several associate their actions and decisions with definitions of themselves. For example, one patient (GJ) says that he would not want life-saving measures because he sees himself as “very independent. I don’t want to rely on anybody, so maybe that’s why I don’t want to be kept alive by a machine. That’s not me.” GJ would like his decisions regarding his treatment to align with his self-perception, and this desire may be heightened by the fact that he has lost many self-defining aspects of his life (which will be further discussed under quality of life).

Another patient (JM) refers to both what she is and what she is not to explain her approach to her treatment. She states that she continues chemotherapy for her cancer, because she identifies herself as a “fighter”: “You’re talking to somebody who’s a fighter, and I’m not gonna give up.” Like GJ, she would like to maintain her sense of self, and makes choices she feels are consistent with her character. In addition, she wants to avoid assuming certain identities. When discussing her use of pain medications, she says, “I don’t want to feel like I’m a drug addict.” She explains that this is not in line with her personality as a fighter.

Other patients also describe the experience of illness as a “fight,” but this holds different meaning for each person. For JM she sees herself as fighting the illness through treatment. In contrast, EA fights for control over his treatment: “Sometimes you do need a break and I’ve taken a break a couple of times. I’ve told the doctor ‘enough is enough.’” For people who have been accustomed to having control over their lives and have now lost a great deal of agency due to illness, patients like GJ, JM and EA seek control in their treatment choices.

It is important to recognize this relationship between patients’ decisions and their identities when discussing approaches to treatment with them. Knowing how people define

themselves can make it easier to explain treatment options to them as well as to understand their choices. Patients may resist beneficial options because they feel that these choices do not align with their self-identities. If these options can be shown to be consistent with their self-perceptions, they may be open to other choices. For instance, being a “fighter” could mean continuing treatment or it could mean being able to ask for a hiatus in treatment. This does not entail manipulating patient perception. Rather, it offers multiple perspectives from which patients may evaluate their situation, broadening their choices during a time when they may feel very limited.

It is also important to understand the threshold where patients feel too much of their identity would be lost. JB, for example, knows how much limitation he is willing to take and not take: “If you want to talk about the end point where I [would choose to] stop eating and drinking and die, I would say, either inability to breathe or inability to eat. I will accept that, you know, I’d be in a wheelchair and I can’t walk. If I couldn’t move my arms and I couldn’t move my legs and had to lie flat, I think that’d be an end point. So I look at those three things.” For JB, he may feel that within some constraints he can still sustain enough of himself to continue living, but after certain points which he clearly defines, he would rather die. Because these points are different for each person, it is helpful to discuss how much of themselves patients can see losing through their illness.

Personal Goals

When faced with the concrete idea of death, there is much for people to consider in terms of what do with their time remaining. In terms of their personal goals, interviewees both adjust past goals and create new ones. As mentioned in the “quality of life” section, patients strive to continue their previous activities. Although most cannot maintain the same level of involvement

that they had before their illness, sustaining some degree of participation is an important goal for patients. Even though she cannot make all the meetings for the police commission which she had previously headed, JM attends any meeting she can and tries to stay in touch with other members of the commission. For FS, muscular chest pain prevents him from playing the horn, a passion he misses greatly. He stays connected to music by listening to it, and retains hope that he may begin to play again, albeit not as intensely as he had before. MG resigned from her position as the vice president of her retirement community, but still speaks to her successor to ensure that things are running smoothly. Because patients strongly identified with these activities before their illnesses, it is significant to them to continue them as much as possible through their illness, even as they recognize their inability to continue to the same degree. With illness affecting so many aspects of their lives, a very important goal is to try to preserve as much of their identities as they can.

Illness also presents an impetus for completing goals that people always had in mind to achieve but had previously put off. In particular, for many interviewees there is a common desire to create. Several interviewees begin to write. HH has a wish to write a story about her childhood, and publish it in her retirement community newspaper. MG wrote a book about her family's history and saw it published by a University Press before her death. After not being able to work due to his illness, FS is now devoting his time to writing, with the intention of publishing a book. For all of these people, the endeavors had been goals in the past, and illness presented the necessary motivation and provided the opportunity to complete them. Thus, though illness is limiting in many areas of patients' lives, it can also push patients to pursue new things that are strongly connected to their desires and needs before becoming ill. In this way, illness can be an avenue for patients to strengthen their sense of selves.

Hopes

Along similar lines to illness opening up new goals, several patients express the hope that they can use their situation for something positive. Two patients donated their bodies to science, with HH saying that she feels it is the “last good thing [she] can do on earth.” EA mentions how important it is to him to be a source of comfort to others who are sick, how he often tells them: “I know what you you’re through firsthand so if you need somebody to talk to, I’m here.” Feeling that their adversity can be beneficial to other people may provide patients with meaning, during a time when they have lost some of what previously gave their lives meaning.

Patients also continue to hope for the same things that were valuable to them before they were sick. These overlap with personal goals in the sense that they are things they wish to achieve, but may be more accurately called hopes in that patients depend largely on having enough time remaining:

EA: I’ve got some things I wanna do yet in life. There’s a couple places I want to go. If something were to happen to me and my time was limited and they put a time limit on it, there’s a couple places I want to visit before I die.

RW: That’s one of my biggest projects—trying to get out to California....I’d like to go before I get any older.

It is important to these patients to feel that they have the potential to do and see a few more things. Even the notion of being able to simply have more time without specific plans is valuable, as evidenced by GJ who “hope[s] for the best as far as living a little while longer,” and JB who is encouraged by a doctor who “offered some hope [when] he said ‘there’s varying degrees of progression and probably 10% of people have quite a long time.’” While it is not always possible to give hope of more time, it may be possible to address what patients hope to have in the time they have left.

Fears and Worries

Many of patients' fears and worries concern the possible inability to sustain their quality of life, pursue their personal goals, or attain their hopes. Understanding what they define as their quality of life and their personal goals—essentially, what how they define themselves—can thus provide great insight into what their fears and worries may be. Patients express fear over losing many of the things previously discussed that they feel are crucial to their lives and identities: physical abilities, self-reliance, mental faculty, and relationships. Several interviewees perceive the loss of these things as a distinct stage of illness they do not want to reach:

FS: I don't want to be bedridden completely.

EM: I hope I don't get to that stage [where I couldn't get around].

EP: If I get so I can't read, that's gonna be the end.

HH: I'm beginning to have trouble with memory...that to me is the final signal that it's time to go.

While illness is a multidimensional experience that encompasses many elements, patients often identify an area of life they most fear will be disrupted—being able to walk, read, or remember. This can be useful to remember when it feels overwhelming to address so many aspects of living with illness with patients. It may help patients to discuss with their care providers the things that they most connect to their identities.

A significant aspect of illness that heightens these fears and worries is the uncertainty about how disease and dying will progress:

EP: I just have to live with it and I don't know what it's going to be like....That's what keeps me awake at night...not knowing.

FS: The patient always lives with this element of uncertainty....it gnaws at you, you know. It's there all the time because you know sooner or later it's gonna come up and bite you....How long are you going to live? How long can you stay alive? Are you going to get these bills paid before time? You know, are you going to finish a book? Are you going to be able to see the grandkids again? What are you going to do next Christmas? Will you be bedridden? When you are bedridden, what are you gonna do about it?

While the unpredictability of the course of illness usually makes it difficult to eliminate patients'

uncertainty, it is important to acknowledge this element of patients' emotion. It affects how they make decisions, from how to treat their illness to how to live day to day.

Decisions of Daily Living

Because there is much uncertainty in how exactly death and dying will occur, people try to complete what they need to do before it is too late. We have seen this sentiment in personal goals, and both areas may contribute to patients' need for a sense of control amidst the uncontrollable forces of illness. Finances often take priority in patients' thoughts about their current situation:

FS: We have to handle the economic situations of cancer, you know...We have to handle income first, so [my wife] and I have to plan how we're going to exist financially.

EM: You have to think of finances too.

Related to these concerns are ensuring that everything is arranged for situations after patients' deaths. This includes, in the short-term, funeral arrangements:

HH: We have a place for my name [in the Grove Street Cemetery]. So we've done all we can do.

WC: I had my daughter and my wife go to the funeral parlor and try to set up funeral arrangements. I want everything taken care of before the times comes...I'd rather have it taken care of so nobody has any gripes about what bills they gotta pay or what's gotta be done or who's gonna do what. I don't want anyone fightin' over anything.

This also includes, in the long-term, the well-being of family members:

HH: You would like to have time to get ready and get things in order. I support my oldest son. He did not have a job in ten years....So, I support him. Because if I don't support him he'll have to be in a shelter and I just can't bear that.

EM: Everything's pretty well-settled for my sons to take over.

MG: I'm trying to leave things in good shape...I have one daughter who is, well, handicapped...I think the other thing I wanted to do was to see my daughter in a satisfactory situation.

JB: [My wife] is 20 years younger than I am, so I have to think about money and finances and things like that.

RL: My only concern is my wife. That she feels taken care of. That she's financially okay...I communicated that to my advisor.

During this period of time where patients require caretaking and lose control of parts of their lives, it appears especially important that they feel capable of minimizing burden on others (by considering funeral arrangements, for example) and of taking care of their loved ones (by ensuring financial stability), especially where they may have a child with special needs.

This becomes more evident when considering the context of patients' day to day lives, where they have to accept help from others. Several interviewees recognize where they require additional assistance, but express discomfort with giving up their independence:

VM: I was always very independent and I came here [to the retirement community] almost three years ago....It took me awhile to make up my mind to sell my house. I was in the house for 61 years and so that was a hard decision, but I had to give up my car and I knew that it was about time for me to come to some place like this.

JB: People told me, "Oh, use the cane." Well, I don't want to use the cane, you know...Well, I fell mowing the lawn out there in the summer of '09, and this winter I used the snow blower because I could hold onto that and go back and forth in the driveway...But they said, "You could break a bone." And then I started thinking, you know I could. I could break my hip and then I'd be in the hands of the orthopods, which I don't want to be, and I would wind up in a nursing home. So I can have "companions" in the house, and so I do.

Independence is a key factor in people's decisions about how to live with illness. For JB, sacrificing some independence (having companions at home) is worth preventing further loss of independence of the future (having to be in a nursing home). The importance of self-reliance is helpful to remember in having discussions with patients about assistance that may be beneficial to them. Placing focus on how assistance can help patients retain their independence, and finding areas of patients' lives where they can still feel control, may help them maintain their sense of autonomous selves.

Having an understanding of how illness affects patients in small ways can be as helpful as acknowledging the broader challenges of being sick. For example, MG struggles with

deciding whether it's worthwhile for her to buy a new bathing suit or glasses, when she is unsure of how much time she has to live. To cope with this uncertainty, she developed a "priority system of what's most important," where she completes tasks she feels are necessary before she dies, like shining up her flat silver to send to her daughter-in-law. Even though these parts of living are usually outside the realm of clinical concerns, they are often what patients think about on a daily basis. To help patients through the broad realm of illness, it is important to enter the context of their daily lives.

Place of Living

When speaking about decisions of daily living, where people live is a common topic. Patients universally expressed preference for staying where they are currently living. There are a variety of reasons for this preference, many of which are the fairly obvious advantages to continuing to live in their own home: RL likes having a large television and his wife's cooking (compared to the food at the hospital and nursing home in which he stayed: "The food is absolutely atrocious in both places"), and GJ wants to die while at home where there is more comfort and familiarity. MG notes that staying in her place helps her continue her routine life even as she is sick: "I tried to lead a fairly normal life, which I think I almost did having an apartment up here."

However, patients often recognize when there is a need to move elsewhere—to hospice, for example. Although some patients like EM hope to not get to the stage where they will need hospice, many appreciate the care a hospice unit provides. According to JA, "they treat you better here... You can go outside and this gives you a good hope." RW agrees that while he is in hospice, "they take wonderful care of you." Even RL, who would rather be at home, finds the hospice staff "absolutely fantastic.... They practically offer you anything you want." Despite the

apparent benefits, it may be difficult for patients to make the transition from where they are living to any new setting, much less hospice which many equate with a stage close to death. It is therefore important to recognize the significance of this and address the physical and emotional changes of moving with patients. One's place of living is closely tied to the kind of life one leads, and thus connected to a person's identity. As has been the case with other topics patients discuss, these changes associated with illness can affect the ways patients perceive themselves.

Family

Another part of patients' daily lives that may be overlooked when considering patient experience is their family. Here again the theme arises of losing one's sense of independent self. EM notes that "you gotta rely on your family for more things." This is difficult for people who are accustomed to being caretakers, as mentioned previously in regards to quality of life. Losing the ability to take care of their loved ones, and needing to be taken care of by their families, may contribute to patients' personal goal of ensuring that their families are well taken care of after patients' deaths. Unable to provide the concrete care to their partners and children, they want to secure continued financial stability for their families.

Patients also seek to protect their loved ones during the period of their illness. People often do not communicate their concerns regarding their illness with their families. EA says that it is hard to know how to talk to his young daughter: "Sometimes I wish I knew what I could tell my daughter. She knows that I'm sick but I don't know how to tell her that...you know what I mean, that I might not be here down the road." When interviewing GJ, his wife is surprised to see him start crying when talking about his ALS: "This is the first time I've seen you break down." He says he has never discussed these things before: "Maybe I don't show it and I want to hide it...I don't want people to worry." EA and GJ are both used to looking out for their

families, and want to continue doing so during their illnesses. To maintain this role of protector, patients may shield their families from the realities of their illnesses at the possible expense of their own need to express and discuss their issues. As care providers, understanding the source of this conflict can help reconcile patients' needs with those of their loved ones. For example, it is important to discuss how conversations about patients' concerns can be as beneficial to families as to patients, and show that this gesture aligns with, rather than goes against, patients' roles as protectors.

Prior Experiences with Death and Dying

Having an identity as a caretaker affects patients in other ways as well. Patients who are accustomed to caring for other sick people, either as a profession or family member, refer to these experiences to contextualize preferences for their own experiences. In particular, people who have seen others endure lifesaving measures, like EM who was a nurse and JB who was an anesthesiologist, do not want the same for themselves:

EM: I've taken care of too many people like that. I know what it is...if you know how it's gonna be, you avoid what you can.

JB: One of my classmates got ALS...he went on a ventilator and he was on a ventilator for over eight years....That doesn't appeal to me. I took care of too many people on ventilators....there's something about lying there, you know, kind of helpless....and, you know, the family dynamics when somebody is on a ventilator is really tough.

People who have cared for ill family members draw on their experience as representative of a kind of life that they do not want. HH notes that her husband, who suffered from Parkinson's, "couldn't feed himself. He couldn't take care of himself in the bathroom...and I knew that he did not want that kind of life." She endorses not wanting to have this kind of life for herself either.

While these offer examples of what patients do not want, some patients also look to other people going through similar experiences for support and guidance on what to

pursue. For instance, JB reads many stories and novels about other people with difficult diseases and draws upon their experiences. From a woman who wrote about having a stroke and subsequent therapy, JB learned about another kind of physical therapy that he then sought out. For VM, she first thought of pursuing hospice from a friend who had been sick: “I would remember my friend who was at hospice in Branford and how pleasant it was...I could see they were very kind. And she needed it, but she didn’t realize that.” In these cases, seeing another person undergo certain kinds of care can push a patient to pursue the same. Several patients who are in support groups emphasize the assistance and insight that other people with similar experiences can offer. People who are in communities with older people, many of whom may be sick, are exposed to situations they perceive as things to consider. These are often not related to end of life measures, but are related to daily living. MG, who lives in a nursing home, says “There are a lot of difficult situations here and the more I hear about them, you know, the more I feel, I just take it as it comes.” It may be easier for patients to recognize the benefits and downsides of aspects of their illness and care, by perceiving someone else going through them. This is an important aspect of support for care providers to keep in mind.

Religion

For some people seeking community during their illness, religion can provide comfort. FS values the “camaraderie” he “find[s] in church,” and RW attributes part of his ability to cope to the Jehovah’s Witness community to which he belongs. It is important to consider whether a person is part of such a community, because religion can affect how a person views their illness and in turn how they approach living with it.

Those who perceive illness in terms of God's role see their experience in the hands of someone else:

EA: Some people are like 'oh well how can you be a person that goes to church and believes in God and stuff like this and you're sick. God must have made you sick.' Well, if God made me sick, then that was my calling to be sick. If I help someday and it's all that I do, it's my time to go home then it's my time to go home. I can't make that decision.

JA: I got somebody [God] who's listening to me. Without God I would've been worse. God's watching me.

WC: While I was in congestive heart failure...God said he would could to get me when it was time. The time is close, he says it's not yet.

For these people, religion has always played a role in their lives, and the presence of religion is stable through their illness. This may be construed as one way patients are able to maintain their identities after falling ill. Although much has changed, their faith remains constant.

For some patients, this strong faith in God eliminates certain worries about how things will turn out. For people like RW and WC, there is less fear of death due to the belief in an afterlife:

RW: I feel that I'm gonna live forever anyway.

WC: I know that when it's time for me to go, somebody is gonna be there for me and they're gonna take my hand and bring me to God, so I know I'm goin' there.

For others, not having this belief can also provide comfort, in the sense that people do not have to spend time considering where they will go:

FS: One's demise is part of existence, you know, and you don't have to worry about, theologically worry about afterlife and where you're gonna be because you don't necessarily accept that there would be one, so it makes things a lot easier, I think.

JB: You might ask do I believe in God? Do I believe in afterlife? And, you know, I really have to go to 'I don't know.'...So I guess I can wait until I get there.

Because religious beliefs can be a significant component of one's identity, it is helpful to consider if and how experience of illness has been affected by a patient's religion. For the religious patients interviewed, religion remained an important part of their senses of

self, which can be a rare source of stability amidst change. It is possible that illness can also change a person's religious perspective, and thereby identity; as such, being mindful of this issue can foster sensitivity to people's identities before and after illness.

Timeframes

While for some there may be certainty about what happens after death, many people experience uncertainty about their time remaining. The prospect of dying often creates a timeframe through which patients then perceive their lives. For example, people set concrete timelines for accomplishing things they have always wanted to do, such as EM's painting and FS's novel. RW, who has always wanted to visit California, now gives himself a deadline to do so: "I'd like to go before I'm 67...so I got two years to plan."

As people seek to fulfill goals connected to the identities they had before becoming ill, they also incorporate illness into their new identities. People associate certain ages with dying, and this helps them frame their dying in terms of natural life. People define themselves by their age, evidenced by the way many interviewees start conversations about themselves by giving their age. And so when age and dying are associated, dying becomes part of their identity.

Many people contextualize their illness and dying in terms of their age:

EM: After all, I'm 93 and I can't expect to live forever. In fact, I never expected to live to 93. So, you adapt to it...it's the way it should be.

HH: But I'm very content with the end of my life being near...I never wanted to be 90 and I'm getting pretty darn close.

EP: I don't know whether I told you or not, but I'm 93. So, that figures into everyone's plans.

Understanding how people perceive their time remaining is an integral part of their care.

Given the relevance of people's self-perception to their well-being and experience, it is useful to ascertain whether a person has assumed their dying as part of their identity.

This is more evident in older patients, while younger patients may have more difficulty reconciling dying with their senses of self.

Memories

As the idea of death makes age register with some patients, it also causes many people to reflect on their lives. This facet of people's lives may not surface during conversation about illness and dying, as these discussions often focus on the present and future. As a result, we neglect people's pasts which can comprise the bulk of their identities. When given the chance to speak freely about themselves, patients bring up a variety of past experiences: childhood, marriage, past work, and travels. Some people wish to capture certain memories in stories and art, to remember them for themselves and to share them with others. These are sources of comfort and sustenance for several patients.

Others mention regrets. Like their pleasant memories, these are often related to family and work. HH mentions regrets about circumstances surrounding her husband's death, and her continuing regret over her son's troubled life. RW laments the difficulty he had in getting work after losing his leg while in the army. While resolution of these conflicts may not be possible, being able to speak about one's past at the end of life is can be an important part of understanding a patient's identity. With this context, patients' approaches and perspectives regarding their illness and dying can be better elucidated.

Attitude and Emotion toward Dying

All of these topics of discussion relate to how patients perceive and process the experience of dying. When speaking about their end of life experiences, people mention their activities, their families, their goals—all of which encompass their approach to living with

illness. They also speak about how they feel about dying itself. This is an important perspective to explore, because how one views the prospect of dying may affect their experience of living with a fatal illness. While most interviewees talk openly and directly about the negative aspects of illness, most try to find reasons for gratitude amidst their situation and the prospect of death.

EM and GJ find that despite their misfortunes, they feel lucky compared to others' situations:

EM: I was glad to know really [that I will die]. Most people don't know, can't tell, and they just go on stringing along until they go. But no, I prefer to know what the chances are and what the odds are probably going to be. It's easier to plan your life that way. And you know you're going anyway, so you might as well know when, if you can. The lady at the table I eat lunch with, she's 97, and she's as miserable as I would be because she just keeps going on and on.

GJ: There are people a lot younger than me that have [my illness]—I happen to be older, and in that case I'm lucky. A friend of mine had it when he was 35...and he went within three years and he left a young family. At least my two children are grown.

GJ is glad that his illness (ALS) has been a gradually progressive one: "At least I lived longer, which I'm grateful for, versus getting it and dying within three years." Other people who have progressed through different stages of disease express similar gratitude for having had a good amount of life after diagnosis, like MG: "What I need to remind myself each day is the thankfulness for the six years I've had after I was first told I had lung cancer." Knowing that people feel more positively when considering their time remaining, it may be helpful to patients for their care providers to discuss the course and progression of disease, and to avoid framing illness as suddenly all-consuming.

With the gradual and often unpredictable progression of illness, many patients develop a day-by-day approach to their situations. It is difficult for people to deal with the uncertainty of how and when things will proceed, and positivity helps them cope:

EA: You gotta take it one day at a time and you gotta look at life different, you know what I mean, you don't take life for granted after you go through something life-threatening....It's hard to go through, and yeah, do people get upset? Yeah people get upset...but you don't have you have to make it worse, you just gotta take it one day at a time.

EM: I have to wait and see. I can't worry about it until it happens....I don't know, so I'm figuring it out as I go along.

JB: My attitude is, as much as possible, when a problem happens we'll solve it.

MG: There are a lot of difficult situations out there and the more I hear about them, you know, the more I feel, I just take it as it comes. All along the way I've felt that attitude was very important, you know, how you look at something colors it a great deal.

Developing positive approaches to negative situations takes effort, and this effort should be encouraged and affirmed by patients' care providers. During a time where people feel vulnerable and less capable, focusing on their strength, ability, and individual agency is a substantial source of coping.

Adjustment

And thus, in discussing topics like quality of life, personal goals, hopes, and attitude toward dying, we have run the gamut of how patients adjust to terminal illness. When faced with an event such as life-threatening disease, the concrete aspects of one's life inevitably changes. How a person copes with this change may be termed adjustment. Without referring to it by name, patients endorse many different ways that they have adjusted to this change to their lives and identities by talking about what they hope to achieve, how they think about their treatment, what they strive for in quality of life.

Often, one of our primary concerns as care providers is patients' adjustment to their health issues, and to address this topic it seems necessary to address the topics above. While not every person may need to discuss each category, considering each of them and whether it is important to a particular patient can help bring to the surface concerns that may otherwise be overlooked. The common thread through these distinct areas has been the notion of a person's self-identity, and how it is changed by illness. Adjustment can be seen as how patients cope with this change, and it encompasses their perspectives on all of the categories discussed here as well as more that is beyond the scope of our project. While it is difficult to cover the full extent of a

person's needs, keeping in mind the theme of identity makes us attentive to the overarching concern of many patients.

Conclusion and Future Implications

The aim of a qualitative study is not to discover generalizations that can be applied to all patients. The value of these interviews stems from insights into individual experience, and from that arises a general framework with which to approach patients. Within that framework, healthcare providers strive to cater to each patient's personal needs and concerns. The results and conclusions of this study, which elucidate the strong connection between illness and patient identity, can give care providers a way to understand patient thoughts, preferences, and decisions.

By first learning how patients define themselves, we can then see how illness affects these self-perceptions, and how this interaction affects patient life. Framing conversations about this period of life around the patient's personal identity can address thoughts that might otherwise go unnoticed, and can help care providers provide more individualized, detailed and informed guidance. This entails paying attention to how patients perceive themselves throughout the experience of illness. When patients are first diagnosed with *any* illness with the potential to become terminal, it is important to ask them to share self-defining aspects of themselves. As patients progress in their illness, care providers should continue to ask them about these aspects, and pay attention to whether changes occur. For example, if a patient strongly identifies with being a mother at the beginning of her illness, it would be important to ask her as her disease progresses if and how her role as a mother has changed.

If patients note changes in these self-identities, it is then essential for care providers to speak with patients about ways to maintain components of their former selves that have been affected by illness. In this way, care providers may consider options to improve patient experience of terminal illness that they may have otherwise overlooked, such as physical

therapy, support groups, hobbies that are important to patients, or things patients want to accomplish before death. Speaking about these issues may help patients, in addition to the care providers, recognize and process the patients' experiences. Care providers can also offer support in affirming the ways that patients can maintain their self-identities despite the challenges of illness.

While this approach may promote general quality of life and self-esteem, it is also applicable to specific aspects of patient care. When discussing topics like treatment options and end-of-life management, many patients make these decisions based on how they perceive themselves. It is important, then, for care providers to recognize how things align or misalign with these self-perceptions in order to best explain the choices patients have and help them navigate their decision-making. For instance, instead of asking patients to simply choose between two treatment options, care provider may ask the patients to explain how each option affects their senses of self. This gives care providers an opportunity to understand how the patients interpret not only their self-identities but also their choices. With more understanding, care providers can have better-informed conversations with patients who are struggling to maintain their identities through a life-changing experience.

This may extend to all patients, not just those who are terminally ill. An acute episode of illness, or a chronic disease, can alter how people feel about themselves in both the short and long term. Being attentive to this by asking questions regarding self-defining factors of patients' lives throughout the illness, and following the trajectory of changes that might occur, can help patients through the process of change.

Given that this study has elucidated a general framework with which to approach patient care and discussion at end of life, future studies may be able to focus on this theme. Interviews

can be structured to target how patients define themselves, and how they would like to maintain their identities through illness. Studies on whether this improves patient and family member satisfaction with end-of-life care can be useful.

Often at the end-of-life there is focus on what has been and will be lost. As JB, one of the patients interviewed, emphasized, it is helpful to patients to consider what things can be maintained. Though these things are different for every patient, the majority are tied to the patient's sense of self. At the end of life, when patients are losing physical life, the spirit of who they feel themselves to be may be the one thing that we can strive to preserve.

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Appendix A: Interview Prompt

Thank you for agreeing to speak with me today. I am interested in learning about the experience of patients who are facing life-threatening illness, and hearing about what their thoughts and feelings are at this period in their lives. We hope that understanding your experience will help other care providers better address the needs and concerns of patients.

The interview is entirely open-ended; I don't have any structured questions to ask. I would like to learn what you are thinking about during this time.

The duration of the interview is entirely up to you. If at any time in the conversation you feel uncomfortable continuing, please let me know. I will be recording the interview, and the recording as well as its transcript will be available to you if you would like to have them. The materials will remain confidential, and any of the content used in our research will use your initials only.

Do you have any questions now? Please feel free to ask me any questions during the interview. We can begin wherever you would like to start.