

**TEMPORALITY AND INFORMATION WORK IN
BONE MARROW TRANSPLANT**

by

Ayşe G. Büyüktür

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Doctoral Committee:

Professor Mark S. Ackerman, Chair
Assistant Professor, Sung Won Choi
Associate Professor Steven J. Jackson, Cornell University
Associate Professor Kai Zheng

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DEDICATION

To my brother, Selim Büyüktür, in loving memory
Your life will continue to inspire.

To my father, Ahmet R. Büyüktür, in loving memory
And my mother, Güniz Büyüktür
Your love and support are in everything I do.

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Chapter 1

Introduction

1.1. Motivation

This study followed from a broad research interest in the properties and processes of information that influence how people experience and make sense of chronic illness in its context, and how these translate into emotions and actions in the course of managing the illness. I seek to analyze such issues with an eye towards practical improvements to facilitate care. From a theoretical perspective, I am primarily influenced by *symbolic interactionism*, a specific approach to the study of human conduct (Blumer, 1969). This approach is rooted in the premises that people act towards things on the basis of the meanings that those things have for them, and that these meanings are derived from social interactions with others and modified through interpretation by the person dealing with the things she or he encounters. Also of particular influence to me are the works of the sociologist Anselm L. Strauss and a number of his colleagues and students¹, in which chronic illness is examined through the concept of *work* – the work done by patients and medical professionals in managing illness – and the organization of work.

The following questions initially motivated this ethnographic study:

How do chronically ill patients come to know enough to effectively, and hopefully comfortably, manage their care and health? How is the state of care and the definition of that state co-constructed by the patient, clinicians, and other interested parties (e.g. the patient's caregivers)? What are the important contextual, informational, and psychosocial issues?

¹ See for example: Corbin & Strauss (1985); Strauss et al. (1997); Strauss et al. (1982)

Time is a defining feature of chronic illness. Michael Bury, the renowned sociologist of health and illness, has argued that patient experiences must be examined within a temporal framework, particularly given the time scale involved in chronic illness and its unfolding or emergent character (Bury, 1991). This argument raises two fundamental questions: How is time experienced in chronic illness, and what other aspects do experiences of time illuminate that are of theoretical or practical significance? With these questions in mind, in this study I treat temporality both as an analytical lens and an object of inquiry. My goal is to examine the questions that motivated this work through the lens of time, or more specifically, the experiences of time. In order to do this, it is essential to identify the relevant temporalities in the clinical context. That is the approach I have taken.

A significant part of a patient's acculturation to illness and treatment takes place in the clinical context, through interactions with clinicians and the information that they provide. This is the type of information work that is of interest to this study. In chronic illness, the interdependent work of all parties – patient, clinician, caregiver, and others – is at the core of health management. The experiences of those involved are necessarily interdependent as well. Hence, in part, this study explores how patient experiences are tied to clinician perspectives and the nature of clinician work. In this respect, the study avoids taking a definitive “patient-centered” or “clinician-centered” approach. I examine different perspectives in conjunction with one another, in order to get a fuller picture of how they influence each other in significant ways and shape the context in which illness management takes place. As detailed in a subsequent chapter describing the field site, caregivers play an important role in the clinical context of this study. They often act in dyadic teams with the patients in the illness process, and their perspectives are intertwined with those of the patients. Hence, in the analysis I provide caregiver experiences and perspectives alongside those of the patients as well.

1.2. Choice of Clinical Context

The clinical context for this study is bone marrow transplant (BMT), which is commonly used in the treatment of hematological malignancies and disorders. The field site is an outpatient BMT clinic located in a large research hospital in the American Midwest. The clinic is where patients are seen prior to their transplant hospitalizations and for most of post-transplant care. The focus of the study is restricted to transplants that involve a donor, called *allogeneic* transplants (“allo” in the clinical setting). Other transplants, called *autologous* transplants, use the patients’ own cells. Allo transplants, which I describe in considerable detail in a subsequent chapter, tend to be significantly more intense and complex. An allo transplant can be characterized as a long-term process that unfolds over several months or years beyond the actual transplant procedure. Due to the complexity of the treatment process and the patient issues involved, BMT specialists closely monitor allo transplant patients at least during the first year following transplant, in most cases longer. The severity of the complications that may arise can range from mild to fatal. Acute and chronic issues caused by transplant, and related treatment, are common occurrences. Patients usually struggle with multiple problems, some of which are intricately interlinked. The context is highly specialized and technical – novel to patients and caregivers. Therefore, an allo transplant requires a lot of learning and health management on the part of patients and caregivers.

It is common parlance in BMT that “no two transplants are the same;” each patient’s transplant experience is unique. Many factors contribute to this variation: the particular transplant protocol that is followed (e.g. different types of chemotherapy may be used prior to the transplant procedure, with different effects), the patient’s medical history and existing co-morbidities, the type and severity of complications that arise, psychosocial issues, and so on. This makes it very difficult to explain issues in generic texts, beyond basic information, that can be handed over to all patients. The usefulness of online resources is limited for the same reason. Given that each case is unique in some ways, it is also challenging for patients to learn from one another. Hence, the primary resource for the patients and caregivers are their BMT clinicians and social workers. The information

received and knowledge gained from them during the process is highly situated, contextually embedded. As the clinicians care for them, the patients get to learn about their own bodies, their own ongoing issues (e.g. medical, psychosocial, functional), how to manage their illnesses, their needs, and how they respond to various interventions. At the same time, both patients and caregivers play central roles in the care process and assume significant responsibilities, especially given the extended outpatient care required in the post-transplant phase. They bring their own observations, information, and expertise back to the clinicians at clinic visits and via phone encounters, which is essential for the clinicians to do their own work. Given the close partnerships with the clinicians, BMT provides an ideal context for examining the type of information work that is of interest to this study.

At the field site for this study, patient monitoring in the post-transplant phase takes place at the BMT clinic unless the patients' current complications require hospitalization. When patients are discharged from the hospital following transplant, they are seen at the clinic several times a week for the first few weeks. The interval between clinic visits gradually extends to once a week, once every other week, once every three weeks, and so on. From a research perspective, this made it possible to follow patients over time to identify informational and contextual issues at different points in the process, and to draw comparisons between patient cases to find common themes from patient experiences. At the same time, the transplant process includes a number of transitional periods. I used two of these as analytical lenses in order to illuminate particular informational, contextual, and temporal issues embedded in the transplant process. Briefly, the first transition involves the patient exiting a period of acute post-transplant issues and entering a period of less clinical-oversight and mostly chronic care concerns. The meaning of this transition differs between patients/caregivers and clinicians. Hence, the transition illuminates different conceptualizations of illness and related information work. The second transition involves the transfer of responsibility for patient care from BMT clinicians to hematology-oncology specialists and primary care physicians. This transition provides insight into challenges with continuity of care following long-term specialty care in a highly technical field. Examining the transition is informative with

regards to the experiences of illness and illness management associated with a critical component of chronic care. It also highlights important organizational considerations.

In summary, the complex and information-rich medical context, highly situated nature of knowledge, close partnerships required between patients, caregivers and clinicians, the long-term process that is involved, opportunity to follow and compare patient cases over time, and the presence of a number of informative transitional periods all made BMT an excellent place for this study.

Chapter 2

Literature Review

Paradoxically, a side effect of advancements in medical science and technology has been an increase in the prevalence of chronic illness, what Gruenberg (2005) calls “the failures of success.” By enabling more people to survive with chronic conditions over longer timeframes, medicine has essentially “produced tools which prolong diseased, diminished lives” (ibid. p.781). Learning about patients’ illness experiences is essential to understanding the impact of illness and medical intervention, and accordingly adapt treatment and clinician advice (Gerhardt, 1990b). Gerhardt, who noted that developments in transplant medicine, drug therapies, and surgery have markedly changed clinical medicine and experiences of illness, argued that there is an opportunity for fruitful collaboration between long-term clinical care and medical sociology. What medical sociology can illuminate is the subjective experience of illness, an “insider’s perspective” that calls for qualitative research with inductive reasoning (Conrad, 1987).

Anselm L. Strauss, whose work this study heavily draws on, is one of the pioneers of the sociology of chronic illness. In earlier work, he collaborated with Barney Glaser to study the dying. Their studies provided insight into dying as a social process and the work hospital staffs do in relation to dying (Glaser & Strauss, 1968; Glaser & Strauss, 1965). Strauss has stated that his studies on chronic illness are essentially “a continuation of the dual focus, begun in the study of dying in hospitals, on work and the organization in which the work takes place” (Strauss et al., 1997, p.x). In effect, he used the concept of *work* in order to study health and illness. He examined, in collaboration with others, the work of hospital staff in caring for the chronically ill, including *machine work* (associated with using, monitoring, maintaining technology/machinery), *safety work* (associated with issues of clinical safety), *comfort work* (associated with tending to physical discomforts), *sentimental work* (associated with psychosocial issues such as trust, composure and identity) and *articulation work* (associated with the collective effort of clinical staff, including planning and coordination to operationalize tasks) (Strauss et al., 1997).

In collaboration with others, Strauss also examined the kinds of work done by chronically

ill patients, both in hospital settings (Strauss et al., 1997; Strauss et al., 1982) and in managing illness at home (Corbin & Strauss, 1985). Their studies showed that while patients engage in all the different types of work undertaken by clinicians (such as machine work, comfort work, sentimental work, and so on), there are also certain types of work that only they can do, such as biographical – or identity – work related to reconstructing one’s life or self by and through illness. Importantly, patients also try to balance *illness work* (i.e. illness-related work) and *everyday life work* (such as housekeeping, marital work, child rearing, or occupational work) in order to maintain what Corbin and Strauss (1985) call a “relative equilibrium” associated with quality of life. Moreover, changes in illness, everyday life, or biography can affect one another, sometimes requiring the patient’s efforts to largely shift towards one type of work while others move to the background.

Importantly, Strauss et al. (1997) noted that pervasive in all activities pertaining to different types of work is *information work*, which they broadly conceptualized in terms of the passing or omitting of information. They discussed information work primarily in terms of “talk” and written information associated with tasks, such as a clinician telling a patient how to position her or his body for a procedure, or providing a report on how a task was accomplished. While Strauss et al. did not examine specific types of information work in detail, they identified a number of considerations in studying these: First, citing Gerson (1981), they noted that the flow of information includes reflexivity and sentiment, and therefore both must be considered in analyses of information work. Second, they stated that sociologists of work “should attack the issues of what information does not get transmitted, by whom, to whom, and why, as well as what information is sought and when” (Strauss et al., 1997, p.253). Third, they argued that information work must be related both to the arc of work (associated with managing the illness) and the contexts in which the work takes place.

A key concept in all these studies is the *illness trajectory* (Strauss et al., 1997; Corbin & Strauss, 1985; Glaser & Strauss, 1968). Illness trajectory refers not only to the course of an illness, or the physiological unfolding of disease, but also to all related work and the

impact on everyone involved, including their relationships with one another. The concept is “above all a means for analytically ordering the immense variety of events that occur – at least with contemporary chronic illnesses – as patients, kin, and staffs seek to control and cope with those illnesses” (Strauss et al. 1997, *ibid.* p.9). At the same time, it allows an analytical focus “on the social context for work as well as on the social relationships affecting the work” (Corbin & Strauss, 1985, p.225). Illness trajectory has been widely adopted as an analytical tool, especially in the nursing literature, and has been used in examining different illness contexts. For example, to examine mothers’ evolving relationships with clinicians in the context of chronic childhood illness (Swallow & Jacoby, 2001), understanding stroke rehabilitation (Kirkevold, 2002; Burton, 2000; Becker & Kaufman, 1995) and recovery from traumatic injury (Davidson & Halcomb, 2005).

Strauss et al. (1997) observed that, while in their own studies they did not make temporal issues central to their analyses (that is, beyond the concept of illness trajectory), temporal features profoundly influence the organization of work. They argued that there is an overarching *temporal order*, which is comprised of the “entire web of temporal interrelationships” that affects the total organization of work activities (p.279). Importantly, they noted that people tend to have their own temporal concerns that profoundly affect their actions, and argued that it is essential to understand individuals’ concerns and concepts of time that are a part of the overall temporal order. This includes, centrally, the conceptualizations of time by both patients and clinicians.

Historically, there has been a much-discussed dichotomy in the conceptualization of time between what have been variously called objective versus subjective time (e.g. Orlikowski & Yates, 2002), *chronos* versus *kairos* (e.g. Murray, 2000; Jaques, 1982), public versus private time (Kern, 2000), and astronomical versus social time (e.g. Nowotny, 1992; Sorokin & Merton, 1937). The fundamental distinction in the dichotomy is the role of human agency in the origins of time as a notion. In particular, “objective” time (or *chronos*, public time, and astronomical time) refers to time as originally

described by Newton in *Principia*² as being absolute, uniform, linear, continuous and quantifiable, for which “clock time” serves as the primary metaphor. In this view, time exists independently of human perception and can only be described in mathematical terms. Kern (2000) noted that the measurability of Newtonian time is what lends an enormous practical value to medical science. On the other hand, this view does not account for individual and social experiences of time. Many of the highly influential social theorists and philosophers of the last two centuries, from Durkheim (1912) and Mead (1932) to Husserl (1964) and Heidegger (1962), representing various schools of thought, have explored the social origins and perceptions of time, which are – unlike Newtonian time – qualitative and highly heterogeneous (Sorokin & Merton, 1937). Their theories underscored the centrality of social rhythms, activities and interactions, as well as individual perceptions of past, present, and future, in conceptions and experiences of temporality.

Based on this historical dichotomy, Toombs (1990) argued that patients experience illness in terms of an ongoing stream of “subjective” time, whereas physicians conceptualize illness as a disease state measured by “objective” time. Toombs stated that the rise of pathological anatomy in the 19th century “de-emphasized the patient’s experience” by equating the ‘truth’ of disease to what was uncovered in the pathologist’s laboratory, thereby giving disease a fundamentally spatial (and objective) rather than temporal aspect (p.227). This, she argued, pushed lived experience to the periphery in the medical world, resulting in the neglect of “illness” in favor of “disease,” whereby it is reduced to X-rays, laboratory studies, and pathology reports. Toombs noted that this fundamental difference in experience between patients and physicians has resulted in a difficulty in communication, and – as Leder (1992) observed – common concerns such as depersonalized medicine and non-compliance by patients. Toombs argued that it is thus essential to examine the lived experience of illness, a central aspect of which is temporality. Drawing on Husserl’s (1964) phenomenology and his example of a musical melody, she described illness as a *temporal object*, which is experienced by the patient as

² For an English translation of *Principia* see Newton & Motte (1995).

a temporal whole that spans past, present and future, rather than isolated now-points (such as a disease state) along a given timeline.

The argument that patients and clinicians have radically different perceptions of illness (Gergel, 2012), and of time in relation to illness (e.g. Borrett, 2013; Gergel, 2013; Morris, 2008), has held over the last two decades, as examined especially in phenomenology. While patient experiences of time have been elaborated (in terms of personal consciousness rather than social construction in the case of phenomenology), there has been consistency in the assumption that clinicians conceptualize time narrowly in terms of “clock time.” This has led some scholars to attempt to reconcile patient perceptions with the “biomedical perspective” (e.g. Borrett, 2013; Gergel, 2013). While overly restrictive in their conceptualization of clinician experiences of temporality, the central argument in these studies is important, because it suggests that patients and clinicians experience time differently with important practical implications for chronic illness work.

Differences in time perception, or the conceptualization of an illness trajectory more specifically, between patients and clinicians, are also implied in the sociology of chronic illness (Loewe & Freeman, 2000; Loewe et al., 1998; Becker & Kaufman, 1995). Becker and Kaufman (1995) compared patient and physician perspectives in the management of the illness trajectories of elderly stroke patients. Their work showed that patients and physicians had different conceptualizations of recovery from stroke, and the role of rehabilitation. In particular, while the physicians viewed rehabilitation as the only option to maximize functional gain, and therefore a patient’s motivation to work at it as essential, they also believed that the potential to influence the illness trajectory was limited by the degree of spontaneous neurological recovery, especially within a period of time after a stroke. In comparison, the patients assumed that their trajectories were open to manipulation as long as they kept working at it, in part due to the vagueness of the information given to them about the role of rehabilitation. Loewe et al.’s (1998) study actually examined aspects of physician narratives in the context of type-2 diabetes, but their discussion of time as an element of the narrative hints at a difference in temporal perspectives between physicians and patients. In particular, they observed that physician

narratives of illness “begin at the moment of onset... and move forward toward a more or less predictable future, either because the patient is thought to have little effective control over the disease (i.e. biology and genetics supersede self-regulation) or the patient is unable or unwilling to regulate him or herself (i.e., environment and culture supersede self-regulation)” (p.1270). Hence, physicians took the view of “organic time” associated with the “progressive and predictable decline of specific organ systems” (p. 1271). In contrast, the authors noted that patient stories tend to begin with a diagnosis, or an event leading up to it, and “move forward in time to the present or an indefinite future” (ibid). In discussing narrative rhetoric, the authors stated that for asymptomatic patients to see the long-term consequences of uncontrolled disease they would have to accept the physicians’ “timeline” of disease (ibid). In later work that compared patient and physician models of type-2 diabetes, though not specifically from the viewpoint of time, Loewe and Freeman (2000) noted that patients did not have a clear long-term perspective on their illness, in comparison to physicians’ view of “organic time.”

The most direct evidence for differences in the temporal perspectives and experiences of clinicians and patients came from Klitzman’s (2007) interview-based study of physicians who became patients with a variety of medical conditions (e.g. HIV, cancer, heart disease). Klitzman found that, once the patient role was assumed, the physicians in his study noticed how radically different experiences of time are between physicians and patients. In particular, the physicians in the study articulated differences between “doctor time,” “patient time,” and “institutional time.” Klitzman noted that the “doctor-patient” participants in the study observed conflicts between different time perspectives that caused difficulties and frustration for them as patients, while they had not noticed these as physicians. For instance, they noted that doctors have limited time to spend with each patient in visits due to institutional demands, while patients generally have more time. They also observed a difference in preferences concerning the timing of events. For example, one of the participants in the study reported that, while she was hospitalized, her clinicians did not think of writing the order for a medication known to cause diarrhea until late in the evening. This resulted in her having to stay up all night. As the schedule continued, she finally had to “go on strike” so that the timing would be altered to

accommodate her own. Other observed differences in time perspectives related to definitions of time (e.g. “long,” “slow,” “soon” can mean different things to physicians and patients), and differences in experiences (e.g. anticipation of test results or uncertainty can cause patients to experience time as “longer”). Based on the findings of his preliminary study, Klitzman stated that differences in the perceptions and definitions of time between patients and physicians is underexplored, and further research is needed as these may have practical implications for patient satisfaction, doctor-patient relationships, how doctors communicate with patients, and patient care itself.

To date, much of the work on time and chronic illness in the sociological literature has focused on the experiences of patients. The significance of temporality was implied in early studies. Goffman (1959), a central figure in the symbolic interactionist tradition, examined the *moral career* of hospitalized psychiatric patients, where “career” referred to a patient’s course through institutionalized illness across stages and allowed for the movement “back and forth between the personal and the public, between the self and the significant society” (p.123). He defined the “moral” aspects of career as “the regular sequence of changes that career entails in the person’s self and in his framework of imagery for judging himself and others” (ibid). The concept of *career* – often called *patient career*, and sometimes *illness career* – has been used by others, especially in the sociology of mental health (e.g. Jones et al., 2009; Pavalko et al. 2007; Gove, 2004) but also in other domains such as pregnancy (Thomas, 2003), end-stage renal failure (Gerhardt, 1990a), and geriatrics (Evers, 1981). In her study of major illness during pregnancy, Thomas (2003) also incorporated Becker’s (1963) notion of *career contingencies* from Becker’s highly influential work on the sociology of deviance. Essentially, contingencies are turning points between different stages of a career, and according to Becker “include both objective facts of social structure and changes in the perspective, motivations and desires of individuals” (qtd. in Thomas, 2003, p.386). Thomas (2003) used this concept in her discussion of the possibility of multiple patient careers in the presence of two or more health conditions (such as illness and pregnancy), noting that the co-presence of health conditions may carry implications for the experience of each condition. She noted that her study was motivated in part by Jobling’s (1977)

description of his psoriasis, in which he noted that a psychosocial career of personal adaptation runs in parallel to “a long career of arduous patienthood” (qtd. in Thomas, 2003, p.386).

One of the most established views on temporality in chronic illness is illness as a biographical disruption. The notion was first proposed by Bury (1982) in a seminal paper in the sociology of chronic illness. It has since been used to examine the experiences of patients in illness contexts as varied as cancer (e.g. Hubbard & Forbat, 2012; Cayless et al., 2010; Hubbard et al., 2010), motor neuron disease (e.g. Locock et al., 2009), chronic fatigue syndrome and fibromyalgia (e.g. Asbring, 2001), HIV infection (e.g. Anderson et al., 2010; Wilson, 2007), and multiple sclerosis (e.g. Green et al., 2007), among others. Based on Giddens’ (1979) concept of *critical situation*, Bury (1982) characterized chronic illness as an event where “the structures of everyday life and the forms of knowledge that underpin them are disrupted” (p.169). Examining the experiences of patients with newly diagnosed rheumatoid arthritis, he highlighted three aspects of disruption in the unfolding of a chronic illness: the disruption of taken-for-granted assumptions and behaviors, disruptions that involve the ill person’s biography and concept of self, and responses to disruption that include mobilization of resources to face the altered situation (ibid). Bury (1991) used the following temporal framework to describe the course of patient experience: the initial disruption of the ill person’s biography, processes of explanation and legitimation, treatment, and adaptation.

The concept of biographical disruption informed Williams’ (1984) notion of *narrative reconstruction*, which emerged from his study on the experiences of “seasoned” rheumatoid arthritis patients, to describe how patients “reconstruct a sense of order from the fragmentation produced by chronic illness” (p. 177). Since the mid-80s, *illness narratives* (Atkinson, 2009; Hydén, 1997; Kleinman, 1989), which by nature represent temporal worlds (Bury, 2001), have proven a prolific area for research. In his discussion on the history of illness narratives, Bury (2001) has noted that the rise of scientific biomedicine, particularly in the 19th century, with its emphasis on the biological causes of disease, diminished the importance of patient experiences – and thus patient narratives.

This is consistent with Toombs' (1990) argument, mentioned earlier, on why patients and physicians have different temporal conceptualizations of illness. On the other hand, Bury (2001) observed that the growing impact of degenerative and chronic illnesses, which reasserts the contingencies of everyday life, as well as the proliferation of information about illnesses on the Internet and other media, have brought patient perspectives back into focus. At the same time, the extensive interest in illness narratives as a means for examining patient experiences of illness has led some scholars to note that physicians' narrative constructions of illness are being neglected and reduced to the *disease narrative* (Loewe & Freeman, 2000; Loewe et al. 1998), which is narrowly focused on "the verifiable manifestations of pathophysiology" (Sharf, 1990, p.222). Hence, a need for exploring physician experiences was identified, in part to examine relevant differences from patient experiences.

While the concept of biographical disruption has been highly influential, informing other strands of work that examine experiences of temporality in chronic illness, more recent work has highlighted some of its shortcomings, and Bury's own analysis has also evolved. For instance, some authors, including Bury and Holme (2002), have observed that age is a mediator in the experience of chronic illness and influences how disruptive the illness is on the ill person's life (e.g. Sanders et al., 2002; Pound et al., 1998). Studies suggested that older people are better able to adapt to new situations, in part because they anticipate illness as inevitable, and therefore do not experience it as disruptive to their biographies. On the other hand, Williams (2000) noted that the notion of biographical disruption is in large part predicated on an adult-centered model of illness that assumes a shift from a 'normal' state of health to one of illness, thereby disregarding illness experiences that begin in childhood and become part of a person's biography. In such cases, he argued, illness does not cause a shift in biography, and continuity rather than change is the nature of the ill person's experience. Williams (2000) used the term *normal illness* to refer to such biographically anticipated illness. However, based on data from an extensive thirty-year prospective study that involved regular interviews with patients who were visually impaired due to diabetes or congenital eye disease, and a retrospective study with elderly patients who had lived with a physical impairment for many years,

Larsson and Grassman (2012) disputed Williams' (2000) argument, stating that neither old age nor a long life with illness make functional losses over time less disruptive. Moreover, the authors argued that biographical disruption could occur multiple times over the course of a chronic illness, rather than only in the very early stages of illness like Bury's original description implied.

In her study of chronically ill patients that spanned nearly a decade (without focusing on a particular disease), Charmaz (1997) described three ways in which the patients experienced illness from a temporal viewpoint, noting that each of these carried implications for the patients' sense of self: illness as an *interruption*, *intrusive* illness, and *immersion* in illness. Charmaz stated that "defining illness as an interruption means looking for recovery" (p.13). In effect, the patients' view of illness and their expectations are aligned more with acute rather than chronic illness, and they may readily assume Parsons' (1951) *sick role*. In Parsons' conception illness is also a disturbance – a deviance, both biologically and socially, from the "normal" (Cockerham, 2012). Consequently, ill people assume the sick role, where they are expected to try to get well. In order to get well, patients take a "timeout" from normal life (Charmaz, 1997). Charmaz noted that patients initially look for complete or near complete recovery. Later, if a patient realizes that complete recovery is not possible, hopes and expectations center on regaining the last stable plateau. Since illness is viewed as temporary, patients do not feel the need to alter their conceptions of self.

On the other hand, illness becomes a permanent part of life for people who experience it as "intrusive" (Charmaz, 1997). It demands time, attention, and accommodation. Hence, illness is necessarily added to the structure of everyday life. In this case illness itself is predictable, because patients expect symptoms and to be treated, and plan accordingly. Time is spent to recognize and control symptoms, to prevent flare-ups, and "normal" activities are slowed down. Charmaz found that people who experience illness as intrusive feel they have limited control over it and over their lives. The feeling of losing control threatens patients' self-conception. In a step beyond intrusive illness, complications, crises, and setbacks lead to "immersion," forcing illness from the

background of daily life to the foreground. In this case, people reconstruct their lives around their illness. Charmaz noted that patients immersed in illness feel vulnerable, withdraw into social isolation, and slip into illness routines. They question their identities; comparing the past with the present and wondering what identity they will have in the future.

As can be seen, much of the work on the sociology of chronic illness and time has focused on the effects on patients' biographies. While acknowledging the significance of information work, as in Strauss et al. (1997), the literature has not extensively addressed information-related issues, particularly with regards to the effects of time. On the other hand, a wider scholarship in Information Science and Organizational Science has examined questions around information work by patients and clinicians, and how temporality and specific types of information work are related in patient care. In the last decade in particular, there also has been growing interest among scholars in Computer Supported Cooperative Work (CSCW) and Human-Computer Interaction (HCI) (with more of the focus on collaborative activities in CSCW) for examining design implications for technologies, and implementing tools that support information work by taking into account temporal elements. I review only the work most relevant to this study.

One area of research has focused on personal health information management (PHIM) by patients, which refers to activities associated with integrating, maintaining, retrieving, and using both personal and health information to stay healthy and combat illness (Civan et al., 2006; Pratt et al., 2006). Pratt et al. (2006) noted that these tasks are particularly challenging for chronically ill patients, who require extended treatment through outpatient care and must manage illness-related work while simultaneously maintaining home and work routines. Consequently, an overwhelming amount of information is accumulated over time, which is inextricably interwoven with personal and professional lives. In their study of the PHIM needs of breast cancer patients, Pratt et al. (ibid) found that the patients commonly organized information based on where they were in the treatment process, such as surgery, chemotherapy, radiation, or hormonal therapy. The patients also organized their information according to events, such as consultations,

treatment episodes, and personal events with implications for cancer care. In subsequent work with breast cancer patients, it was shown that many activities associated with PHIM take place when patients are on the go and away from their personal health information collections, resulting in *unanchored information work* (Klasnja et al., 2010). Hence, studies have revealed multiple ways in which patients organize and manage information, each of which has temporal underpinnings. In studies concerning the design of technologies to support patient information work, underlying temporalities have been key considerations. For instance, mobile tools have been shown to help patients manage unanchored information work (Jacobs, 2014; Klasnja, 2011). Chen (2011) has observed the need to support the temporal arrangement of chronic care cycles – the repeated clinic/homecare cycles by which patients receive, synthesize, and use information. Whereas Hayes et al. (2008) have argued that the design of technologies to support cancer care could be informed by information needs in the different phases of the care process, which they broadly identified as screening and diagnosis, initial information seeking, acute care, no evidence of disease, and chronic disease management.

Studies have shown that if healthcare technologies are to be successfully integrated into everyday life, designers must consider not only the disease and treatment-oriented perspectives of clinicians, but also the knowledge and everyday lives of people (Ballegaard et al., 2008), including broader social and community contexts (Kaziunas et al., 2013). Ballegaard et al. (2008) referred to this as accounting for the “citizen perspective,” which they said should supplement the “clinical perspective.” Whereas from a clinical perspective a new technology is often meant to fix a health-related problem, the citizen perspective emphasizes a person’s ability to live a normal everyday life. The authors noted that people manage illness in the context of their everyday routines, and either rely on these routines rather than on clinical knowledge, or integrate clinical knowledge about their disease into their everyday routines. For instance, in one study it was found that elders manage their medications not based on a clinical perspective that is focused on the name, dosage, and exact timing of medications, but through a set of personalized spatio-temporal arrangements and routines in their everyday lives that provide a structure and rhythm to medication intake (Palen & Aalokke, 2006).

A study that examined insulin use by pregnant diabetic women also supported these findings (Ballegaard et al., 2008). Consequently, Ballegaard et al. argued that healthcare technologies must be designed to minimize the disruptive nature of new technology, thereby supporting continuity in everyday life.

With respect to clinician work, among the central themes relating time and information work has been the temporal organization and coordination of activities, including shift changes and handoffs, between clinical staff. A series of studies in surgical departments that centered on the planning of operation schedules have highlighted the social nature of time and how this can affect information work (Bardram et al. 2006; Bardram 2000; Egger & Wagner, 1993). These studies showed that temporal coordination is a negotiated action that is influenced by inherent social structures, such as power differentials, and shaped according to prevailing temporal conflicts and interests in the organizational context in which work takes place. Abraham and Reddy (2008) showed that such conflicts also pose challenges to coordination between clinical and non-clinical staff, such as in the patient transfer process within a hospital. The authors observed both unintentional and intentional lack of information sharing between clinical and non-clinical staff, where information sharing was influenced by the lack of awareness of work practices, the prioritization of local clinical work over interdepartmental activities, and status differences between clinical and non-clinical staff. Between clinicians, temporal conflicts often arise from the distinct work trajectories of physicians, nurses, and other healthcare providers that run parallel to one another as the illness trajectory of a patient unfolds (Munkvold & Ellingsen, 2007). Common information spaces (such as care plans) intended to help with the coordination of activities can be viewed as intermittent points where different work trajectories intersect (ibid).

Distinguishing temporal rhythms from temporal trajectories as “generic patterns of coordination and action” (such as morning rounds on a hospital ward), Reddy and Dourish (2002) showed that established rhythms of work also provide a means to seek and coordinate information. They noted that conflicting rhythms could lead to different expectations about the availability of information; for instance, a new resident physician

unfamiliar with the rhythms of nursing work seeks information from a nurse who is just beginning a shift – information that she does not yet have. In a later study, Reddy et al. (2006) elaborated on three temporal features that influence the organization of work and information seeking by clinicians: *temporal trajectories* (structured timeliness of activities, events and occurrences created by the illness trajectories of patients); *temporal rhythms* (reoccurring patterns of work at the collective level); and *temporal horizons* (the ways in which people organize their work using their knowledge of likely future activities). Paul and Reddy (2010) found that clinicians often make sense of information collaboratively, and that this type of activity also has a temporal component – what they termed a *sensemaking trajectory*. A sensemaking trajectory depicts how the sense made of a situation by one clinician, or group of clinicians, influences the sense made later of the same situation by others. Finally, although they focused primarily on joint scientific work rather than work in a medical context, Jackson et al. (2011) showed that collaborative activities are organized around four separate kinds of temporal rhythms: organizational, infrastructural, biographical, and phenomenal rhythms. As defined by the authors, biographical rhythms refer to the life choices and circumstances of participants in collaborative work. Infrastructural rhythms derive from the nature and temporal features of the built environment. Phenomenal rhythms pertain to objects under study (e.g. rate of tumor growth). Lastly, organizational rhythms refer to the temporal structures embedded in the organizations and institutions that govern the work of the participants.

In another central line of work, clinician shifts and patient handoffs constitute specific kinds of temporal coordination. They are an important problem in the *continuity of care* (Fitzpatrick & Ellingsen, 2013), which has informational, relational, and management aspects (Haggerty et al., 2003). The vast literature on patient handoffs in information science and organizational science predominantly focuses on continuity of care with respect to clinician work, and indicates transitions as weak points in care processes (Cohen & Hilligoss, 2008). In CSCW, studies of shift changes, documentation practices of clinicians, and use of electronic health record systems have highlighted a need to support complex information assembly and disassembly processes associated with patient handoffs (Hilligoss, 2010; Zhou et al., 2009; Tang & Carpendale, 2007), and challenges

concerning the documentation of information for long-term use (Zhou et al., 2012; Zhou et al., 2010).

Another type of transition of patient care, one that generally involves more complex information processes, has been gaining increased attention in recent years: transition of care for patients with chronic illnesses following long periods of specialty care. This type of transition usually involves transfer of responsibility for patient care to primary care physicians, and has generally been examined under the premise of cancer survivorship in the medical literature. In 2005, the Institute of Medicine (IOM) published a report titled “*From Cancer Patient to Cancer Survivor: Lost in Transition*,” highlighting challenges associated with this transition. The IOM report suggested a more active role for patients during transitions, which is largely overlooked in the literature on patient handoffs. Patient and caregiver experiences and participation in transitions have largely been neglected in favor of problems with transfer of care from the viewpoint of clinicians.

In summary, the review of the literature in this chapter has focused on two central themes: the experience of time in chronic illness, and the relationship between temporality and information work. The literature on the sociology of chronic illness has largely examined the first of these themes, while the broader literature in information science, organizational science, CSCW, and HCI has provided insight into the second. In the next chapter, I highlight gaps in our current understanding of time in chronic illness and its relation to information work, and state the open questions that I address in this study.

Chapter 3

Research Questions

As described in the previous chapter, Strauss et al. (1997) have observed that temporal features, including individuals' concerns and concepts of time, profoundly influence the organization of work associated with the management of illness trajectories in chronic illness. In this study, I focus on the effects of temporality – especially the experiences and conceptualizations of time by patients and clinicians – specifically on the organization of information work, and particularly the collaborative information work between patients and clinicians that enable the patients to learn about their illnesses and manage their care effectively as their illness trajectories unfold.

As I discussed in the literature review, the literature on the sociology of chronic illness has emphasized the central role of time in the experience of illness, mostly from the patient perspective. It has also been indicated that patients and physicians conceptualize time differently, with potential practical implications for patient care. On the other hand, much of this literature has overly-restricted the clinician perspective to “clock time,” arguing that clinicians focus on “disease state” (which they measure using clock time) as opposed to “illness.” There is a lack of empirical studies that closely examine the multiplicity of temporality, especially in relation to an unfolding illness trajectory, from the perspectives of both patients and clinicians within the same clinical context. Moreover, the practical implications of differences between the temporal perspectives of patients and clinicians have been largely underexplored (Klitzman, 2007).

At the same time, as I discussed in the literature review, while acknowledging the significance of information work (as in Strauss et al., 1997), the literature on the sociology of chronic illness has not extensively addressed information-related issues, including the effects of temporality on information work. A broader literature encompassing information science, organizational science, CSCW, and HCI, has examined the ways in which temporal elements influence illness work by patients (e.g. how patients organize personal health information based on temporal features) and clinical work by medical professionals (e.g. how temporal features affect the organization

and coordination of collaborative work activities), with particular emphasis having been placed on how people organize, seek, and make sense of information. However, there is a gap in the literature regarding the ways in which temporal features affect the organization of information work associated with how patients learn about their illnesses and how to manage these through their interactions with clinicians, and how the state of care and the definition of it are co-constructed in collaboration with the clinicians and other interested parties in patient care via this information work.

In this study I examine the temporal experiences and perspectives of both patients and clinicians in the context of allogeneic bone marrow transplant for adult patients. In particular, I investigate the ways in which the illness trajectory is experienced, envisioned, and anticipated from a temporal viewpoint by the different participants. Since the caregivers in this context often act in dyadic teams with the patients, and their temporal perspectives often match those of the patients, in the analysis I provide caregiver experiences and perspectives as well. In addition, I examine the implications of underlying temporalities on the organization of information work, particularly the work necessary to enable the patients and their caregivers to gain knowledge and skills so that they can effectively, and hopefully comfortably, manage illness as the illness trajectories unfold. Consequently, I focus on the following questions:

Research Questions: *What are the relevant temporal elements in the BMT clinical context that influence how patients, along with caregivers, learn about illness and how to manage it? What informational issues are of significance? What psychosocial issues are of significance? What is the unfolding process of information need, information access, and understanding? What implications do patient and clinician perceptions of time have, if any? How is the state of care and the definition of that state co-constructed by the patient, clinicians, and other interested parties (e.g. the patient's caregivers)?*

Chapter 4

Methodology

This study is based on a two and a half year ethnographic fieldwork at an outpatient clinic for adult bone marrow transplant patients. The clinic is located in a tertiary research hospital in the American Midwest. Data collection included non-participant observation, formal semi-structured interviews, informal interviews, and document collection. In addition, I was granted explicit permission by a caregiver – and the patient – to use the blog the caregiver kept of the patient’s transplant journey for over three and a half years. I followed this patient’s case over time, had informal conversations with the patient and caregiver, interviewed the caregiver, and did an in-depth analysis of the blog with 397 entries, including almost daily entries for the first few months post-transplant.

Between May 2012 and November 2014, I conducted over 700 hours of observations at the BMT clinic. This included clinic visits by patients both in the pre-transplant and post-transplant phases, observations in the clinic’s teamroom where clinician teams work on patient visits, and informal interviews with patients, caregivers, and clinicians. For observations of patient visits, I regularly shadowed a BMT physician’s clinic team³ throughout the study period. As detailed below, BMT is a long-term process that unfolds over several months or years beyond the actual transplant procedure for a patient. Shadowing a physician’s team consistently over time provided the opportunity to observe patient cases as they progressed through the transplant process, allowing insight into the BMT process itself and how patient issues and informational issues evolved. On a less frequent basis I shadowed two other physician teams, including one that particularly focuses on the management of chronic graft-versus-host disease (GVHD), a specific complication from allogeneic transplants. The goal for the observations of patient visits was to gain insight into clinician work, patient-caregiver-clinician partnerships in care, and how patients and caregivers learn about BMT and illness work (Corbin & Strauss, 1985). The observations have been very informative about the collaborative process

³ Team structures are discussed in detail in the next chapter. They generally consist of a physician, one or more physician assistant or nurse practitioner, and a clinic nurse.

through which clinicians, patients, and caregivers navigate the transplant process, the types of questions they have for each other, and the information clinicians particularly want patients to know. Overall, I was able to observe more than sixty unique patient cases. I observed multiple visits by twenty-seven patients over time. Sixteen of the visits I observed specifically took place around day 100 post-transplant, which is a timemarker in the transplant process. Additional observations of visits leading up to the timemarker, as well as visits beyond the timemarker provided further insight into the transition.

Besides observations of clinic visits, observations of clinical activities in the teamroom have been crucial for understanding clinician work, especially how they work in teams. The teamroom is the place where clinician teams discuss patient cases before (and sometimes after) visits, which led to an understanding of how clinicians view patient issues and individual patient cases. Conversations regarding patient and caregiver personalities, styles, and preferences usually happen in the teamroom, which has been important for understanding informational issues. I also intermittently observed support group meetings organized for BMT patients and caregivers. Conversations at these meetings provided insight into the overall BMT process and the difficulties that patients and caregivers encounter.

Interview data includes detailed semi-structured interviews with 16 patients (8 female, 8 male), and 9 caregivers (5 female, 4 male), regarding their transplant experiences. Each interview lasted one to two hours. Of the patient interviews, 10 were conducted with patients whose cases I observed over time. Seven of the caregivers interviewed were the spouses of patients I interviewed, and couples were interviewed together except in one case. One of the caregivers interviewed has experience with the transplant process at a different transplant center than the field site for this study. However, the themes that emerged from the interview are similar to the ones I identified through others. Of the patients interviewed, 14 were six months or farther out of transplant at the time of their interviews. Of the caregivers, 7 had patients who were more than six months post-transplant. The remaining 4 patients and caregivers were closer to day 100 in the transplant process at the time of their interviews. I could not conduct additional formal

interviews around day 100. Some interviews scheduled with patients who were around day 100 post-transplant were postponed until later in the transplant process due to the appointment schedules of the interviewees. Relapses, hospitalizations, and scheduling conflicts prevented other interviews. I was able to gather additional information about the day 100 transition in the interviews conducted with patients who were farther out in the transplant process. I also had informal conversations with patients and caregivers approaching day 100 or just beyond the timemarker, instead of formal interviews.

Interview questions broadly covered the following topics, although a semi-structured approach was followed: (1) Background information, including the original diagnosis for which transplant was had and how far out the patient is from transplant. (2) Post-transplant experiences, including how life has been as a transplant patient/caregiver since hospital discharge, a typical day and new routines, how the recovery has progressed, significant complications and hospitalizations, how the complications unfolded, and information needs regarding complications. (3) Ongoing issues, including chronic complications and how these are managed. (4) Emotional challenges and responses to transplant. (5) Whether the patient/caregiver feels the transplant has changed her or him in any way. (6) Managing social interactions with others, including seeing/talking to family, friends, and outsiders. (7) Caregiver roles, responsibilities, and division of labor in the household. (8) The most challenging aspects of transplant, including whether or not these have changed over time. (9) The timing of information. (10) Given the transplant experience, particular advice the patient/caregiver would give someone who is just preparing to get a transplant. (11) Whether the patient/caregiver feels comfortable in managing care. (12) Plans to go back to work. (13) How the patient/caregiver feels about transitioning care to a hematologist-oncologist and/or primary care physician. (14) The kinds of questions the patient/caregiver has about transplant at the time of the interview.

Besides the interviews with patients and caregivers, informal interviews were conducted with 6 BMT physicians, 8 physician extenders (i.e. physician assistants and nurse practitioners who work in teams with BMT physicians), 5 clinic nurses, 6 transplant coordinators, and a clinical research coordinator throughout the study period. Two

experienced social workers and a social worker in training also participated in informal interviews that focused on their work, and the overall BMT experience for patients and caregivers, including information-related issues.

All but two of the interviewees (a patient and a caregiver) agreed to be audiotaped during their semi-structured interviews. I took detailed handwritten notes during the interviews that were not audiotaped. Throughout the study period, I documented clinic observations and informal interviews through extensive field notes. Two informal interviews, one with a BMT physician and the other with a social worker with the clinic, were audiotaped with permission. I omitted personal identifiers from field notes and removed them from interview transcripts.

Document collection at the field site included copies of all educational material – in print format – provided to the patients and caregivers prior to transplant. These include a patient treatment handbook that describes the transplant process in detail, with information on preparing for transplant, the transplant hospitalization, the post-transplant phase, and potential complications. Also included is a handbook for donors, which describes stem cell collection. Other educational material includes a guidebook for caregivers written by former BMT caregivers, and a guidebook for patients on coping with late effects from transplant in the survivorship phase. Additionally, I obtained blank copies of paperwork given to the patients and caregivers prior to transplant, such as a formal caregiver agreement form (described in detail in the next chapter) and information on preparing a living will. I also received a copy of the handout provided to the patients and caregivers at their education session with a transplant coordinator⁴ prior to transplant. I was able to observe an education session in which the material on the handout was reviewed with a patient and caregiver by their transplant coordinator.

I analyzed the data using grounded theory methods (Glaser & Strauss, 1967; Charmaz, 2006) in an iterative process. I used open coding particularly in the first few months of fieldwork to identify emerging concepts and themes from the field. I periodically exited

⁴ The roles of transplant coordinators are described in the next chapter.

the field for a few weeks to review the data. I wrote analytical memos to gain more insight into emerging themes, and considered links between themes via axial coding. Once I identified core themes of interest, data collection became more targeted, and I used selective coding in the data analysis. I iteratively checked emerging understandings against the data, particularly against the presence of any negative cases. I verified the concepts and themes that emerged from this process through subsequent field observations and interviews.

All names and individually identifying information were anonymized in my field notes and interview transcripts. All names used in the text below are pseudonyms. This study was approved by the Institutional Review Board of the University of Michigan.

Chapter 5

Clinical Context

5.1. Overview of Bone Marrow Transplant

Bone marrow is the spongy tissue inside flat and long bones that contains stem cells that develop into blood cells. These include red blood cells (which transport oxygen around the body), white blood cells (which fight infections) and platelets (involved in the clotting of the blood). BMT is commonly used for the treatment of hematological malignancies and disorders, including cancers such as leukemias and lymphomas, whereby diseased or destroyed stem cells are replaced with healthy ones harvested from the patient or a donor. If a transplant is done using the patient's own stem cells it is called an *autologous* ("auto") transplant. If stem cells from a donor are used, the transplant is classified as an *allogeneic* ("allo") transplant.⁵ This study focuses on the experiences and care of allo transplant patients, for whom the transplant process is more intense, complex, and involves risk for specific acute and chronic complications. Patients with acute forms of leukemia or disorders such as myelodysplastic syndromes (in which the bone marrow produces insufficient amounts of mature, normal-functioning blood cells) or myelofibrosis (which is characterized by scarring of the bone marrow that prevents the production of sufficient amounts of blood cells) are often candidates for an allo transplant. Disease diagnosis is usually done by a hematologist or hematology-oncology ("hem-onc") specialist, who initiates treatment and refers the patient for a BMT consult to see if transplant is a feasible and appropriate option.

An allo transplant involves a long-term process that unfolds over several months or years. It is generally the only hope for a cure or for slowing down disease progress. It is an aggressive approach that takes its toll on the patient's body. The transplant itself is preceded by chemotherapy, often in high doses and sometimes along with radiation therapy, which essentially wipes out the patient's bone marrow. This pre-transplant chemotherapy/radiation therapy is known as *conditioning*. Its purpose is to eradicate the

⁵ Transplant can also be *syngeneic*, meaning the donor is an identical twin of the patient.

diseased cells, make room for donor stem cells, and suppress the immune system to prevent rejection of the donor cells. For a period of time after conditioning therapy the patient becomes dependent on red blood cell and platelet transfusions. Since white blood cells that constitute the immune system are also killed off, the patient becomes at risk for all kinds of potentially life-threatening infections. Consequently, a strict regimen of antibacterial, antifungal, and antiviral medications ensues. The marrow is rescued by transplanting donor stem cells. As these begin to produce new blood cells the patient's immune system is in effect gradually replaced with that of the donor. Allo transplant patients are placed on anti-rejection medication for months, sometimes for years. These medications have side effects that must be managed.

An important complication from allo transplants is known as graft-versus-host disease (GVHD), in which the donor's immune cells ("graft") view the patient's body ("host") as foreign and attack it. The location (e.g. skin, mouth, intestines, liver, eyes, lungs, etc.) and severity (mild, moderate, severe, or life-threatening) of GVHD varies from patient to patient. About half of allo transplant patients get some form(s) of GVHD. The disease can present in acute and/or chronic forms: acute GVHD usually occurs within the first 100 days post-transplant, whereas chronic GVHD tends to develop later and can last a lifetime. However, it is possible for acute GVHD to emerge later in the process, and for chronic GVHD to emerge earlier. Acute GVHD commonly affects the skin, gastrointestinal tract and/or the liver. Skin GVHD usually manifests as a rash and can progress to cover a large surface of the body (25% or more). GVHD in the stomach and intestines can lead to hospitalization with nausea, vomiting, and/or diarrhea, where oral intake of food and fluids may be withheld during treatment (i.e. the patient may be placed on nil per os, NPO: "nothing by mouth"). In liver GVHD, changes occur in liver function and the patient may become jaundiced. In contrast to the "quick and angry"⁶ nature of acute GVHD, chronic forms tend to emerge rather stealthily and last longer. While chronic GVHD can occur pretty much anywhere in the body, some of the most common manifestations include dryness and/or sores in the mouth, dryness and/or irritation in the eyes, changes in skin pigmentation (though some changes look more akin to eczema)

⁶ As described by BMT physicians.

and/or tightening in the deeper layers of the skin that may restrict range of motion, narrowing in the esophagus that could cause difficulty swallowing, pain and stiffness in the joints, and shortness of breath due to lung damage. Some of these symptoms are more obviously worrisome; however, seemingly innocuous ones (such as dryness in the mouth or eyes) can be surprisingly debilitating.

Since GVHD results from the donor's immune cells attacking the patient's body, steroids and other immunosuppressive drugs (i.e. drugs that suppress the immune system) are used to treat and prevent it. At the hospital where the field site for this study is located, a procedure called Extra-Corporeal Photopheresis (ECP) – a form of light therapy – is also commonly used against GVHD. In this procedure the patient is connected to an apheresis machine (in some ways similar in concept to a dialysis machine) and blood is temporarily drawn out of the body through an intravenous line. White blood cells (which cause GVHD) are then separated from other blood cells, treated with a photosensitizing agent that particularly affects a type of white blood cell, and then exposed to ultraviolet light. The blood is returned to the body and the treated white blood cells die off due to the procedure, resulting in an overall calming effect on the immune system. Each ECP session lasts about two to three hours. ECP is generally used alongside immunosuppressive drugs rather than as the first-line treatment for GVHD. It is also important to note that a mild form of GVHD can actually have a beneficial anti-cancer effect (known as graft-versus-leukemia, GVL), because donor cells also recognize any remaining cancer cells as foreign and attack these. The GVL effect can therefore reduce the risk of disease relapse. Still, GVHD must be kept in check.

One of the trickiest aspects of allo transplants is balancing the prevention and treatment of GVHD with other potential complications, most notably infections that can prove fatal. Steroids and other drugs that suppress the immune system (used against GVHD) also render the patient's body more prone to infections. For this reason, patients stay on prophylactic antibacterial, antiviral, and antifungal medications until they are off immunosuppression. Despite these drugs there is still significant risk for infection. Additionally, long-term steroid use can cause other serious side effects, such as muscle

wasting, osteoporosis and bone fractures, high blood sugar that can lead to diabetes, thinning of the skin and slower wound healing, and adrenal insufficiency (where the body quits making a sufficient amount of steroids on its own). Other side effects, such as mood swings, high blood pressure, and fluid retention (swelling, commonly in the lower legs, that can be considerable) can occur even with short-term steroid use. Side effects from steroids, along with side effects from any of the other medications a patient is taking, and any co-morbidity that the patient has must be managed. The hope is that the donor's cells and the patient's body will eventually "learn to get along with each other," as the BMT clinicians sometimes say. As this happens immunosuppressive drugs are gradually tapered off; they cannot be stopped cold turkey. If GVHD presents when the dose is reduced, clinicians may increase the dose for a period of time before trying to taper it down again. Ultimately the goal is to get the patient off all immunosuppressive medication as soon as possible and with minimal side effects and complications. In some cases this takes months. In others it takes years. For some it never happens. The balancing act while the clinicians work on this is challenging; to the non-clinician observer, at times it seems as much an art as science.

So far this overview of BMT has described the kind of physical burden transplant can place on patients, but there is also the significant emotional toll of going through such a difficult process. In subsequent chapters I highlight psychosocial experiences in more detail. In terms of managing illness, much of patients' – and caregivers' – time prior to transplant and especially in the first few months post-transplant is spent in clinical settings: going for numerous tests and procedures, seeing clinicians, getting infusions, and so on. After transplant, they need to manage upwards of 20 medications (many taken multiple times a day), follow infection precautions, self-administer home infusions that take hours to complete, adhere to specific dietary and lifestyle restrictions, keep up with daily chores, and stay physically active to a certain degree despite the fatigue that comes with treatment. It is a grueling process. Due to the aggressiveness of the treatment and the serious risks it involves, the severity of the diseases for which transplant is done in the first place, and the heavy physical and psychosocial (not to mention financial) burden, BMT recipients constitute some of the toughest clinical cases. The care process is

correspondingly complex for all involved. I describe the transplant process in more detail after a brief description of the clinic.

5.2. The Clinic

The field site for this study is an outpatient clinic for adult bone marrow transplant patients⁷ located in a tertiary research hospital. The clinic is just down the hall from the BMT inpatient ward. This arrangement allows the main parts of the adult BMT unit to be largely collocated on one floor of the hospital. The close proximity enables clinicians to move easily between inpatient and outpatient as needed. The ward and the clinic are largely isolated from general traffic inside the hospital; the entire floor is typically quiet.

The clinic has a waiting room with two front desks where patients check in. Armchairs, as well as a number of computer stations, are available for patients to use while waiting for their visits. For the visits patients are taken into the enclosed clinic space through a main door. Once inside, the first stop is one of the medical assistant (MA) workstations where MAs collect basic information such as vital signs (blood pressure, pulse, temperature, breathing rate), weight and height. The MAs then take each patient to a private room or the shared infusion area. Neutral colored, well-lit hallways divide up the clinic space, which includes 11 exam rooms, a teamroom for clinicians, 4 rooms specifically designated for procedures such as bone marrow biopsies, offices for transplant coordinators (whose roles are described below), offices for other staff members (e.g. the clinical nurse supervisor, administrative staff), a small staff work center equipped with computers, equipment rooms, a staff lounge with a kitchenette and lockers, a nourishment room for patients and family members, several other rooms dedicated to specific needs (e.g. medical gas hold, soiled utility room), and a number of separate restrooms for staff and patients. In one corner of the clinic space there is a shared infusion area with 10 infusion chairs arranged side by side (these can be partitioned with curtains and each has its own television set), as well as 10 private infusion rooms with a single hospital bed in each. The clinic also has two checkout desks inside the enclosed

⁷ Pediatric BMT is separate.

clinic space. The electronic health record (EHR) system, essential to work in the clinic, is accessed via computers that are distributed throughout each of these spaces, including every exam room.

Exam rooms are small, each containing an exam table, a computer workstation for the clinicians, two chairs next to the workstation (usually occupied by a patient and caregiver), and two cabinets (one containing small medical supplies and the other paper forms, such as order forms). There is also a sink, as well as bottled hand sanitizer attached to the wall. The private infusion rooms are similar to exam rooms, except with hospital beds (instead of exam tables) and television sets. In the shared infusion area, clinicians may see patients while they are getting their infusions. In these cases the clinicians draw the curtains around the chairs for extra privacy.

The teamroom for the clinicians is a rectangular room equipped with twelve computer workstations arranged along three walls. The workstations are not formally assigned to particular clinicians, but they prefer to use the same one on the days they are on clinic duty. On the fourth wall there is a whiteboard on which the day's schedule is actively updated as patients arrive and leave. There are also two tables at the center of the room. I used one of these throughout my observations at the clinic. On the other table is a coffee machine, and clinicians often place snacks on this table as an indication that anyone is welcome to these. They frequently receive small gifts from patients and caregivers as a token of their appreciation: thank you cards, memorabilia, home-baked cakes and cookies, or produce from their gardens. These are displayed or shared on this table. Except for the computers the room is scant on technology; printers and scanners are the only other equipment frequently used.

The teamroom is central to a lot of the activity associated with patient visits and clinic life. It is where clinician teams (described below) on duty on a given weekday work. It is the place for collocated coordination and collaboration, and a lot of friendly banter between staff members. It is where clinicians discuss and work on their patients' cases, and recount anecdotes of funny or frustrating incidents. It is where they openly share

delight in finding that a patient is doing particularly well and sadness at news of relapses, hospitalizations, and deaths. It is where they talk about their own lives, their children and vacations and sports. It is where lunch is ordered as a group and eaten at workstations while trying to keep up with the fast pace of the clinic day.

The clinic staff includes: attending physicians, physician assistants and nurse practitioners (collectively referred to as *physician extenders*, both groups have training in transplant patient care and their job roles are the same at this clinic), a clinical research coordinator, transplant coordinators, clinic nurses, infusion nurses, medical assistants, and social workers. Sometimes there is a clinical pharmacist on site. There are no fellows or residents on the regular physician staff although they are occasionally seen at the clinic. Attending physicians (from now on, *physicians*) carry primary responsibility for the patients.

5.3. The BMT Process

An allogeneic bone marrow transplant is a process that involves much more than the transplant itself. Next, I provide an overview of the transplant process. Given its complexity, I provide a simplified rendition for the sake of clarity.

5.3.1. Pre-transplant

Prior to the transplant, in this site each patient works closely with three staff members at the BMT clinic: a BMT physician, a transplant coordinator, and a social worker.

The BMT process begins with a patient's first transplant consultation appointment. In the clinic setting this is called a *new patient visit*. At this visit the patient meets with a BMT physician to discuss the specific case and learn about bone marrow transplant. If the patient eventually decides to move forward with transplant, this particular physician is responsible for the patient's care throughout the process.⁸ In my observations, almost

⁸ The only exception to this is when the patient is hospitalized in the BMT inpatient ward (e.g. for conditioning chemotherapy, transplant itself, the first few weeks post-transplant, and possible intermittent hospitalizations thereafter). This is because BMT physicians rotate to go on service at the inpatient unit. There is the chance that the patient's BMT physician will be on service during part of the patient's hospital

every patient is accompanied by at least one other person – usually the prospective caregiver – at these visits. Most often this is the spouse or significant other, at other times it is a parent, child, sibling or friend. Typically the person who accompanies the patient is the one who takes notes on a notepad or piece of paper as the physician provides consultation. During the consult, the physician collects information about the patient’s medical history, conducts a physical examination, provides information about the patient’s disease and the type of transplant that could be done, emphasizes the potential benefits and risks of transplant, and takes questions from the patient and caregiver. The consult unfolds in the form of a conversation rather than a one-way information transfer between the parties involved. At the end of the consult the physician usually makes a recommendation for or against transplant. In some cases the physician may choose to discuss the case further with colleagues in BMT or a different specialist (e.g. if co-morbidities exist, such as concerns with the heart or liver) before making a recommendation. However, if transplant is a feasible option and the patient is considering it, the physician will have the patient meet with a transplant coordinator.

Transplant coordinators – or clinical nurse coordinators – are primarily responsible for managing the extensive pre-transplant evaluation required of each patient, as well as overseeing donor searches. Additionally, coordinators provide patients with appropriate consent forms (e.g. for donor searches and clinical trials) and give transplant education that covers the basics. One coordinator is assigned to each patient. Although a patient’s BMT physician and coordinator work together, the coordinator is the patient’s main contact person at the clinic until the patient is admitted to the hospital for transplant.

A pre-transplant evaluation includes: organ function tests, and assessments of disease status, psychosocial issues and caregiver support. Of these, organ function tests (e.g. echocardiogram or multigated acquisition scan of the heart, pulmonary function tests for the lungs, markers for kidneys and liver, and so on) are important because the

stay. Otherwise the physician currently on service oversees the patient’s care while the patient is in the hospital. Note that the physician on inpatient duty still sees non-hospitalized patients in clinic, usually in the afternoons after rounds on the ward are completed. Some clinic visits may be covered by one of the extenders and/or the nurse who work with the physician and consult with the physician as necessary.

chemotherapy/radiation therapy that precedes a transplant can damage various organ systems and medications taken post-transplant, as well as GVHD, can affect organ function. All allo transplant patients are also required to see a dentist.⁹ Dental care prior to transplant is important to identify and treat any oral infections before the patient's immune system becomes compromised due to chemotherapy and other medications. Assessment of disease status is done via bone marrow aspirate and biopsy. The patient's disease should be in remission (i.e. there is no evidence of disease in the blood and marrow), or there should be less than 5% blasts (i.e. diseased cells) in the marrow for the transplant to move forward. In order for this to happen the patient receives chemotherapy (apart from and prior to the conditioning therapy) that is overseen by the patient's hematology-oncology physician instead. As described below, psychosocial issues and the level of caregiver support available to the patient are assessed by one of the clinic's social workers. The patient's transplant coordinator arranges all referrals to specialists, receives all results, ensures that the patient's BMT physician reviews all results, and keeps an evaluation checklist for the patient.

In addition to all this coordination work, transplant coordinators manage donor searches for allo transplant patients. A search includes having healthy siblings – who are the preferred donor candidates – tested to see if there is a good match in the underlying criteria for transplant (called *HLA*¹⁰ *typing/matching*). In some cases others in the patient's family – such as a child or parent – may be tested. However, siblings are the most likely to be good matches. If a patient has no siblings or an appropriate sibling match cannot be found, the patient's information is entered into a registry to search for unrelated donors. According to transplant coordinators, there is an 80% chance that an unrelated donor will be found for a patient who is Caucasian. For African Americans the likelihood is 50%, and it is usually lower for patients of other ethnic origins. Furthermore, not all donor matches turn out to be eligible in the end (primarily due to health considerations), some candidates refuse to donate, and some are not available within the timeframes in which the matching patients must get their transplants. The

⁹ Other evaluations include gynecology for female patients and ophthalmology.

¹⁰ Human leukocyte antigen

donor search process therefore has its own challenges.

As stated previously, a third staff member who gets involved in the process in the pre-transplant period is a clinical social worker. The social worker is responsible for assessing the patient for transplant eligibility particularly with regards to psychosocial issues and level of caregiver support. Among the priorities of the social worker are to learn about any history of mental illness and behavioral issues (including past or current talk therapy or medication therapy), and to determine the kinds of coping strategies that have worked for the patient in the past. Other assessment includes past or present substance abuse and any abuse or intimidation in the home environment. Additionally, the social worker ensures that the patient has a living will, either a pre-existing legal one or one provided by the clinic for the patient to complete. For the assessment the social worker meets with both the patient and the caregiver(s) – often together but sometimes separately as well. Besides the assessment, the social worker reviews the basics of insurance. Allo transplant patients are told not to expect to return to work for one year. Unless the patient is retired this generally comes as a shock and many other arrangements must now be made: how to take medical leave from work, how the caregiver(s) should coordinate responsibilities, and questions of income and insurance. The social worker is an important resource for the patient and family in approaching these issues.

At this clinic no transplant moves forward unless the patient is cleared by the social worker. For this to happen the patient must also have a satisfactory and formal caregiver plan in place. A detailed agreement that outlines caregiver responsibilities is used for this purpose, and both the patient and caregivers must sign the document. The clinic requires at least two caregivers for the transplant to proceed; one primary caregiver and at least one backup in case the primary is unable to fulfill responsibilities at any given time. According to the agreement, the following are among the responsibilities of caregivers: First, at least one caregiver must accompany the patient at all times – literally 24/7 – in the first two to three months after transplant or for as long as required by the patient's BMT physician (prior to transplant, the typical timeframe provided by BMT physicians is the first 100 days post-transplant). In this period of time determined by the physician, a

caregiver must reside with the patient within a set distance – in miles – from this particular hospital so that the patient can be brought to the hospital quickly if there is an emergency. Since the clinic receives patients from all over the U.S. state in which it is located, as well as out of state patients, this means relocation for many people. Additionally, a caregiver must attend hospital discharge training following the patient's transplant, learn how to give injections and intravenous (IV) medications and fluids at home¹¹, review transplant materials provided by the clinic, accompany the patient to all appointments and coordinate transportation, review the patient's medication schedule and assist as necessary, follow infection precautions, manage food preparation and daily living functions, ask clinicians questions to ensure that information is understood correctly, and follow the treatment plan set by the transplant team.

According to an experienced social worker, at times up to five individuals can make up a caregiver plan in order to accommodate other responsibilities caregivers may have, such as families and work. In the vast majority of the cases I observed at the clinic, one person – most often the spouse or significant other – was the primary caregiver and performed all of the specified duties. There were some cases where children, parents, siblings, friends, and even strangers (e.g. from churches) fulfilled the responsibilities, sometimes sharing roles with others. I also encountered two cases in which the patients had hired caregiving from a professional agency. However, more recently the clinic has had reservations about such arrangements due to concerns that agencies cannot provide adequate caregiving services for BMT patients, as well as concerns about patients dropping these services prematurely for financial reasons. Clinic observations also show variation in the type and extent of caregiver involvement. Some caregivers are fully committed to the process and serve as “the eyes and ears” of the patients, to borrow one patient's description. A BMT physician also commented that he knows several patients “who would surely have died long ago” without their caregivers' active involvement in the process. On the other hand, there are many patients who choose to fully take control while the caregivers largely remain on the sidelines. I am also aware of one case in which

¹¹ For example, all allo transplant patients require home infusions of magnesium for the first few months post-transplant.

caregiver support disintegrated to the point of non-existence because the patient was perceived as being “bossy” by the caregivers.

Given the various pre-assessments, requirements, and the many factors considered in making a final decision, how many patients actually go through transplant? At this clinic roughly half the patients who come for a transplant consultation ultimately get a transplant. In all, about 200 to 230 transplants are done here every year. Approximately half of these are allo transplants. In most other cases the physicians recommend against transplant or the patients refuse transplant. Common reasons for a physician to recommend against transplant are the presence of high-risk (i.e. potential risks outweigh any benefit a patient may get from transplant) and cases in which the patient’s disease can be managed without a transplant. For example, there are cases of myelodysplastic syndromes where the disease has not progressed (or may not progress) to the point where transplant is necessary, at least not urgently. In other rare cases – seen perhaps only a couple of times a year – the patient is not cleared for transplant primarily because a satisfactory caregiver plan cannot be formulated. Finally, another possibility is that an appropriate donor cannot be found. On the other hand, there are occasionally cases where the patient – otherwise eligible for transplant – refuses to go through with it due to concerns about quality of life post-transplant or for financial reasons. According to a social worker, patients who refuse transplant for financial reasons often do so to protect their families from the economic burden the transplant would place on them. However, the majority of patients eligible for transplant choose to go through with it. Almost all of the patients and caregivers I encountered have stated that the decision was a “no-brainer” or that they “didn’t have a choice really” because the choice would have been between life and death.

If a patient is willing, a donor is available, and all pre-transplant evaluation is satisfactory, the patient is seen twice more at the BMT clinic before being admitted to the BMT inpatient unit for conditioning therapy and the transplant itself. In the first of these clinic visits, which takes place one to two weeks prior to hospitalization, the patient meets only with the transplant coordinator. The coordinator provides more detailed

information about what to expect in the hospital and the particular treatment schedule for the patient (e.g. what chemotherapy agent will be given on what day). The patient's final clinic visit takes place 24 to 72 hours before being admitted to the hospital. At this visit, called a *pre-transplant visit*, the patient usually meets with both the transplant coordinator and the BMT physician. The coordinator confirms that all requirements for transplant are met and all paperwork is in order. The physician's goal is to ensure that the patient is healthy enough to enter the hospital for transplant; therefore a final evaluation is done to look for any brewing issues such as potential infections. If there are any such concerns the physician may have to postpone the transplant, which does happen. The possibility of having the transplant postponed can make patients and caregivers anxious at pre-transplant visits, especially if transplant has been postponed before or if the patient has been dealing with issues (e.g. recurring infections) that could potentially result in postponement. In my observations, at this point patients and caregivers really want to move forward with the process. Postponement causes discouragement, frustration, and emotional distress since a lot of expectation is built up during the preparation period. If the physician does give the final approval, the patient is admitted to the BMT ward on the scheduled day.

5.3.2. Transplant

While in this hospital for transplant, each patient works with the inpatient BMT team: the BMT physician currently on inpatient rotation, extenders and nurses on the inpatient staff, and social workers. It is possible that a patient's primary BMT physician will be on service by chance during part of the patient's hospitalization. Otherwise the inpatient staff is separate from the clinic staff. The clinic, which is the primary site for this study, is therefore only peripherally involved at this stage. However, it is important to know about this stage for a more complete understanding of BMT.

Prior to transplant each patient gets a catheter surgically placed through a vein in the chest, which remains with the patient until about 100 days post-transplant, or until the patient's BMT physician approves its removal. The catheter is used for blood draws,

transfusions, IV fluids and medications (including chemotherapy), and the transplant itself. As described previously, once a patient is admitted to the hospital, a period of chemotherapy (sometimes along with radiation therapy) called *conditioning* precedes the transplant. This takes, on average, five days. Then there is usually a day or two of “rest” before the transplant takes place. Unlike solid organ transplants, such as heart, kidney or liver, in BMT the transplant is nonsurgical; the new cells are infused much like a blood transfusion.¹² Many clinicians, patients and caregivers characterize the transplant as “anti-climactic” for this reason; given all the buildup and stress associated with the overall process. The day of the transplant is marked as *day 0* for the patient and is used as the reference point to situate the patient’s transplant trajectory (e.g. the day before transplant is *day minus 1*, thirty days after transplant is *day plus 30*, and so on). Transplant patients sometimes refer to day 0 as their “birthday.” For example, an allo transplant recipient commented that she has three birthdays: her own “original” birthday, her transplant day, and her donor’s birthday.

BMT patients remain in the hospital on average for two to four weeks following transplant. Clinicians expect *engraftment* to occur in about two weeks after the procedure. This means that the transplanted cells are growing and producing blood cells. Once the physician on inpatient rotation confirms engraftment, in the absence of any complications and if the patient is able to tolerate fluids, food, and oral medications, the patient is discharged from the hospital. The patient and caregiver enter the period in which they are required to reside in close proximity to the hospital until the patient’s BMT physician lifts this requirement.

5.3.3. Post-transplant

Once discharged from the hospital a patient is seen regularly at the BMT clinic at short intervals, initially several times a week. In all outpatient post-transplant care, the patient’s BMT physician holds ultimate responsibility for the patient. All physicians have their own clinic days – certain days of the week on which they see their patients (e.g. Tuesdays

¹² The transplanted cells find their way to the bone marrow.

and Fridays for one physician). These post-transplant clinic visits are called *return visits*. Other clinicians involved in the care of *return patients* include the physician assistants and nurse practitioners (i.e. the extenders), clinic nurses, infusion nurses, and medical assistants. Social workers also work with patients and caregivers after transplant. While they may follow-up with patients and caregivers on their own initiative, social workers most often get involved if alerted by BMT clinicians that the patient or caregiver is or may be experiencing psychosocial difficulties – for example, anxiety, depression or caregiver burden – or that there is a crisis situation such as disease relapse or conflict between a patient and caregiver.

For several reasons, post-transplant patient care is more demanding in the first few months, roughly in the first 100 days, after transplant. First, the patient is on high dose immunosuppression (commonly the drug Tacrolimus, called “Tacro” in practice) that must be monitored closely. Tacro taper usually begins around day 100. Second, the patient frequently receives IV infusions, such as fluids, blood products and electrolyte infusions. The caregiver usually manages some of these at home, such as the magnesium infusion that is necessary because Tacro leeches magnesium from the body. At the beginning these home infusions of magnesium take up to six or more hours to complete, every day, significantly limiting anything else the patient and caregiver can do. Over time the patient is gradually transitioned to magnesium pills; as more pills are added, the IV dose is reduced (i.e. infusion time also decreases). If there are no complicating factors, this transition to pills could begin as early as two weeks after hospital discharge. The need for supplementing magnesium lessens as the physician begins to taper down the Tacro dose. In the meantime however, the clinicians closely follow magnesium and other electrolyte levels by having these checked regularly at clinic visits.

A major reason behind close follow-up by BMT clinicians at this site in the first few months is the possibility of acute GVHD and infections. A patient may get any or all forms of acute GVHD described earlier in this chapter. One of the key priorities of clinicians is to identify and treat GVHD before it gets rapidly out of control. If GVHD emerges the patient is usually started on steroids (often in high doses), and may get ECP

treatments as well. Side effects from steroids (and other medications) must be managed. Since the patient is on high dose immunosuppression in this period – regardless of whether or not steroids are added – the risk for infections is also very high. Since any infection can become life threatening very quickly, these also must be identified and treated immediately. The rate of re-hospitalization is higher in this early period post-transplant due to acute GVHD, infections, and other potential complications. When a patient comes for a clinic visit, the BMT physician and an extender who works with the physician see the patient in one of the private infusion rooms, where an infusion nurse also manages IVs as needed. Usually the same extender sees the patient with the physician at each visit, which allows the extender to develop familiarity with the patient's case and the patient to have continuity of care. At these visits, if the physician identifies or suspects any acute issue that requires intervention in the hospital the patient is admitted directly from the clinic to the BMT inpatient unit. Such re-hospitalizations are very common; in fact, many patients get hospitalized multiple times, sometimes remaining in the hospital for weeks.

In the first few months post-transplant, a patient is also under many dietary precautions and lifestyle restrictions. For instance, driving is prohibited until the BMT physician clears the patient for this activity. There can be multiple reasons why it would be dangerous for a given patient to drive, however, one common reason for all patients is that Tacro tends to affect reaction time. Patients are told that the earliest they could begin driving is by day 100, although in practice the actual timing varies on a case-by-case basis. Some patients begin to drive a little sooner, while others remain under this restriction longer. Traveling beyond a certain distance from the hospital is also forbidden until the physician lifts this restriction. A major reason for this is that the patient may need to be brought to the hospital very quickly if a complication occurs. Depending on the particular means of transportation there could also be high risk for infection (e.g. the risk would be higher on a crowded bus or airplane compared to the patient's own car).

Many of the other restrictions are primarily infection precautions. These are simply too many to recite here (especially those pertaining to the handling, preparation, cooking,

storing, and transportation of food), but examples include the following: the patient must not have fresh fruits and vegetables, open buffets, or drinks from soda fountains at restaurants. Deli lunchmeat or cheeses that are not pre-packaged must be avoided. Pepper and other spices must not be added to food unless they are added before the food is cooked. Fresh strawberries and raspberries, raw broccoli, cauliflower, and sprouts must not be eaten. Leftover food must be thrown away after two days. Hot foods must not be served at room temperature. Food must not be thawed at room temperature. Besides these and numerous other food-related precautions, the patient needs to also avoid infection by wearing a mask in crowded places and washing hands (and using hand sanitizer) religiously. The patient must not come in contact with anyone who might be ill, including children who might have friends at school who are sick. Via the transplant handbook provided by the clinic, the patient is also instructed not to hug pets. The patient must not garden or mow the lawn (due to risk of catching a fungal infection from soil) or even be in the vicinity if others are doing these chores. The patient must not use a vacuum cleaner (to avoid dust), de-humidifiers (to avoid stagnant water), or anything that might irritate the lungs. There are also other precautions that are not always related to infection risk, such as avoiding direct sunlight (especially without sunscreen) because the sun can trigger skin GVHD. These and other restrictions the patient – and caregivers – must follow, and how long each of these remains in place depends on the patient’s progress. Since there are too many potentially harmful things to avoid, it is not possible for the patient and caregivers to know or understand all of these. Therefore, they are encouraged – repeatedly – by BMT clinicians to call the clinic if they are unsure about anything and to bring questions to clinic visits. In my observations, patients and caregivers often have questions about these and other matters related to daily life at clinic visits and in phone calls to the clinic.

If acute issues resolve and the patient’s condition becomes more stable, the interval between visits gradually increases. The timemarker commonly given by BMT clinicians for this to happen is day 100 (although the timing varies in practice depending on each patient’s progress). If this is the case, the period around day 100 involves several changes, and is in some respects an important transition in the transplant process. First,

this is the time when the BMT physician starts to taper down the Tacro dose. Second, the patient has another bone marrow biopsy (as all allo transplant patients do around day 100) for re-assessment of disease status. In my observations, patients and caregivers are usually quite nervous as they wait for the results of this biopsy and – as expected – extremely happy to receive news of a biopsy free of disease. Clinicians also check the percentage of cells that are of donor versus patient origin. Ideally, 100% of the cells would be of donor origin. Third, the patient begins to come for clinic visits usually once a week or every-other-week. Fourth, this is the time when it is expected that the physician will lift the requirement of having to live in close proximity to the hospital; hence, an out of town patient can go home although there is still the need to travel frequently for clinic visits. In my observations, patients and caregivers put a lot of weight on being cleared of this restriction. This is a topic that comes up frequently in interviews and clinic visits. They are always incredibly excited to hear the news that they are cleared of this restriction. Fifth, other restrictions – such as on driving and traveling – are also lifted, albeit gradually. For instance, the patient is instructed to begin driving only within his or her neighborhood, to avoid going on highways, and to have someone in the passenger seat the first couple of times. If the driving is safe and no other complications emerge, the patient can make more changes (e.g. drive longer distances). Similarly, patients are still advised not to travel long distances or use crowded transportations. Other precautions and restrictions may be somewhat relaxed at this time as well, but due to continuing infection risk these constitute more of a gray area. Therefore, this is the time when patients and caregivers have lots of questions about what they may or may not do – or eat (which tends to be a popular topic with patients). Unfortunately, not all patients get well enough to be cleared of restrictions at this time. Not meeting the day 100 “milestone” – in various ways – is generally a cause for discouragement and a big disappointment for patients and caregivers.

In this site, another significant change around day 100 is that patient care transitions to more structured physician teams. In caring for patients at this stage, each BMT physician works with one or more extenders and a clinic nurse in what constitutes the core teams for these return visits. These teams are fixed: each physician works with the same

extender(s) and clinic nurse on clinic days, allowing for constancy in teams and continuity in patient care. The extenders and clinic nurses are very knowledgeable about transplant related issues and the particulars of individual patient cases. If a physician has more than one extender on the team, the extenders also strive to have a good knowledge of the physician's other patients for whom they are not primarily responsible. This way they can fill in for each other at other times if necessary. Besides return visit duties (described in the next section), clinic nurses are responsible for phone encounters with their own team's patients from the time the patients are discharged from the hospital after transplant. Therefore, clinic nurses are patients' and caregivers' primary contacts when they call the clinic with questions. Since this happens often and is repeatedly encouraged by clinicians from the beginning – to prevent complications and to catch an emerging issue as soon as possible – clinic nurses play a critical role in bridging patient care between clinical and non-clinical settings.

Beyond the period around day 100, a patient may have no significant complications, or one or more issues going on simultaneously. Among the most important of these is chronic GVHD, which can emerge as the Tacro dose is tapered down. If this is the case, the GVHD is addressed – as usual – with immunosuppressive medication and possibly ECP treatment (the light treatment previously described). The patient's BMT physician determines the frequency of ECP; an example treatment schedule would be to have two sessions every other week (i.e. four sessions per month) until the frequency is reduced. Each session would take about two to three hours in the hospital, but the procedure can be done on an outpatient basis. It should be noted that continuing immunosuppression means continuing risk for infection; therefore, prophylactic medication regimens and infection precautions remain in effect.

As described earlier in this chapter, some of the common forms of chronic GVHD include the skin, mouth, esophagus, eyes, liver, joints, and lungs. Each of these has the potential to affect a patient's quality of life significantly. For instance, if there is tightening in the deeper layers of the skin or GVHD in the joints, range of motion – particularly in the hands, arms, legs and feet – could be restricted. If there is esophageal

GVHD, the patient may have difficulty swallowing, and may need to undergo a procedure to address the narrowing in the esophagus. This procedure helps some patients. One patient I talked to reported having difficulty swallowing even after the procedure. If there is GVHD in the mouth that causes severe dryness, the patient may have difficulty eating without washing food down with lots of liquids. In a clinic visit a patient reported having to sip water all the time. The dryness could also lead to dental problems that require significant dental work. If there is GVHD in the eyes, the eyes may feel very dry and/or irritated. Mild dryness and irritation is sometimes managed with regular eye drops; however, if the GVHD is severe it could be quite debilitating. For example, at a clinic visit a patient reported that he has to take timeout everyday – multiple times a day and for ten minutes each time – to clean out “goopy stuff” that builds up in his eyes. If a patient has eye GVHD that causes severe dryness, more advanced treatment options are considered; for example, getting tear ducts plugged by an eye doctor, using more advanced types of eye serum, or getting a special type of lens – which are quite expensive – specifically fitted for the patient’s eyes to help keep them moist. While all types of GVHD can be potentially debilitating, lung GVHD is the kind that makes BMT physicians particularly nervous. Once impaired, damage to the lungs is often irreversible. Moreover, if the patient experiences other assaults to the lungs, such as fungal infections or pneumonias (which many patients do), the situation becomes even more difficult and potentially deadly. BMT clinicians want to catch lung GVHD as early as possible and diligently assess for symptoms, such as shortness of breath on exertion. Finally, if there is GVHD in the liver it could be largely asymptomatic but also potentially quite dangerous. Laboratory tests alert the clinicians to the fact that something is going on in the liver. This could be GVHD or another problem, such as iron overload from having had too many blood transfusions. In general, BMT clinicians continue to work on pinpointing the exact cause of a symptom or test result in this period, since different complications can cause similar manifestations.

Besides problems with GVHD, a patient may continue to experience one or more side effects from immunosuppressive drugs and other medications that affect daily living. For example, Tacro causes tremors in many patients (particularly in the hands) as well as

neuropathy (associated with nerve damage) that can result in pain or numbness (particularly in the hands and/or feet). A patient also reported being “jumpy” while on Tacro, and having difficulty staying in crowded rooms with lots of noise. Tacro can also affect kidney function, which must be monitored. From the early days of transplant all patients are instructed to drink several bottles of water everyday to keep their kidneys healthy – something many patients find difficult to do. As described earlier, steroids cause many side effects as well, especially if used long-term. If there is muscle wasting, the patient will likely require physical and/or occupational therapy. Oral or IV medication may be used to strengthen the bones, and insulin shots to manage high blood sugar. If there is fluid retention (swelling, often in the lower legs), it is usually partly treated with a diuretic (i.e. water pill) though this does not always solve the problem completely. Other drugs, such as the antibacterial or antifungal medications, could have side effects as well. Hence, all of these potential complications – and others – must be assessed, treated, and followed at clinic visits (and at home by the patient and caregiver) both in the early and later post-transplant periods.

It is important to note that there are two physicians at the BMT clinic who are experts on chronic GVHD and run separate chronic GVHD clinics. These clinics are held in the same clinic space; the GVHD physicians have their own clinic days. Other BMT physicians consult with the GVHD experts as needed or refer their patients to one of the GVHD clinics for an assessment and consultation. GVHD clinics run in the same manner as regular BMT clinics: the physicians work closely with extenders and clinic nurses. Although this practice is not quite consistent, many patients are seen by either one of the GVHD clinics around six months post-transplant, earlier if significant chronic issues begin to emerge. These visits are called *new patient visits* because the patients are seen for the first time at a GVHD clinic. A new patient visit has two primary purposes: to get a baseline assessment of GVHD for the patient, and to provide education on chronic GVHD. The assessment includes a grip test (to test for strength), a pulmonary function test for the lungs, and measurement of oxygen saturation before and after a two-minute brisk walk. Additionally, the patient fills out a survey to rate – on a scale – how much he or she has been bothered by symptoms associated with GVHD in the past month (such as

those pertaining to the eyes, mouth, joints, and so on). As part of this assessment, the patient also provides information for mood screening. Before seeing the patient the GVHD physician reviews the results of the assessments in the teamroom. During the visit the physician probes further for symptoms and also conducts a physical exam that particularly focuses on GVHD. For example, the patient is asked to go through several exercises – such as lifting the arms to the sides and above the head – to assess any problems with range of motion. As stated previously, an important aspect of the new patient visit is that it is essentially an education session where the GVHD clinician provides the patient with a general overview of the different forms of chronic GVHD. A clinician noted that this education session is particularly important because at this stage of transplant BMT clinicians usually see patients less frequently (i.e. the interval between visits is longer); hence, patients take on much more of the responsibility for tracking and reporting potential issues. Furthermore, chronic GVHD tends to emerge rather stealthily, and some symptoms are such that they are not always immediately attributed to GVHD. For instance, a patient may begin to feel tired when climbing stairs and think it's because he or she is deconditioned, while it is possible that this is a sign of GVHD in the lungs. The patient education is to sensitize patients to the types of things they should pay attention to.

If a patient has ongoing GVHD, the GVHD physician may continue to see the patient in clinic although the patient's regular BMT physician still serves as the primary BMT doctor. In one arrangement, the primary BMT physician and the GVHD physician see the patient at alternating visits; for example, a visit with the BMT physician, followed by a visit with the GVHD physician three months later, then another visit with the BMT physician three months after that.¹³ The patient is therefore expected to come for follow-up visits as long as transplant related issues linger. The ultimate goal for the physicians is to get the patient off all immunosuppression without having any active chronic GVHD. In the ideal scenario the patient would be off immunosuppression six months after transplant; however, this is relatively rare. Patients are often given the one-year

¹³ This visit schedule is an example. Visits with the primary BMT physician can be more frequent if there are multiple issues going on with the patient.

anniversary of their transplants as the possible timemarker for when they might be off immunosuppression. However, several years out of transplant many patients continue to have chronic GVHD in one or more forms and possibly to varying degrees, and continue to be on immunosuppression. Transplant related problems could also emerge years after the transplant. GVHD could flare up and disappear, only to flare up again. In general, chronic issues following a transplant tend to eventually reach a plateau, often referred to as “the new normal” for the patient. Still, things may improve or worsen.

If a patient’s condition improves or stabilizes in a manageable way, the interval between visits continues to extend (i.e. after day 100, visits are usually once-a-week, then every-other-week, then three weeks, one month, six weeks, and so on). In the meantime, BMT clinicians expect part of patient care – primarily issues outside their expertise – to begin transitioning to a primary care physician. Around the first-year anniversary of the transplant the risk of disease relapse decreases significantly, although it is still a possibility. If major complications do not exist the patient is seen in clinic every few months, with the goal of bringing down the visits to once a year. As the process winds down, the patient’s BMT physician expects the patient to complete the transition out of BMT care. This means that a primary care physician and a hematology-oncology specialist should follow the patient instead.

5.4. Clinician Roles

In order to provide a better understanding of the clinical context, next I include a deliberately simplified and somewhat sequenced rendition of work at the BMT clinic. The simplification is necessary because clinician work is very complex in this setting.

As detailed in the previous section, patient visits at the BMT clinic include new patient consults, pre-transplant visits, and post-transplant return visits. New patient visits and return visits are often scheduled on different days – although there are exceptions – because new patient visits take considerably longer than return visits (approximately 1-1.5 hours versus 20-25 minutes on average). Besides visits with clinicians, patients also

come for procedures, such as bone marrow biopsies, and infusions.

As stated previously, BMT physicians hold ultimate responsibility in patient care throughout the transplant process. Because each patient remains under the care of the same physician from the very beginning, physicians get to know their patients very well. In fact, I have heard countless times and independently from different clinicians (including physicians, extenders, and nurses) that it is very important to them “to know” their patients. In my observations, “knowing” encompasses at least the following: The particulars of a patient’s medical case, how the patient’s body responds to interventions, the patient’s psychosocial state, personality and details of the support system (especially caregiver support), home and life circumstances that might affect patient care, and income and insurance constraints that require workarounds. Whereas most details of the medical case are assembled in the patient’s medical record, much of the other information is often in the minds of the physician and other clinicians who work with the patient. Essentially, the care that a patient receives is personalized from the particulars of the treatment to the way information is delivered. For example, over time a physician will find that a certain medication causes side effects or adverse reactions in a patient’s body whereas a different medication with the same indication does not. He will notice that GVHD tends to emerge in particular ways in this patient and keep an eye out for it, making sure that the patient and caregiver know how to recognize symptoms and when to call the clinic. He will remember that the patient travels a long distance to get to the clinic and so coordinate his own appointments with visits with other specialists. He will observe that the patient has a tendency to downplay concerns or under-report problems and take this into account in his own probing for information and his decision-making. He will know whether the patient has a nervous tendency, positive or negative attitude, or an uptight or laid-back personality. He will notice whether the patient seems to benefit from some humor in the conversation or prefers a blunt approach. He will note whether a gentler or stricter style works best to ensure that the patient is more compliant with treatment and any other issue related to health and safety (e.g. “I don’t want you to drive” or “It would be better if we waited a little longer before you make the trip down to Florida.”). He will gauge caregiver involvement and what roles the caregiver assumes

during transplant to work with the patient and caregiver most effectively. He will even get to know family issues; for example, that the patient got into an argument with the caregiver. I have even observed a physician serve as the mediator in an argument, giving his time separately to the patient and the caregiver. Hence, there really are countless ways in which a patient gets to be “known.” This begins at the initial transplant consult but unfolds over time. A physician often tells his new patients that he “doesn’t know [them] yet.” The same goes for the extenders and nurses. In their capacity as the patient’s care providers, the entire care team serves as much more than medical experts – their work involves much more than applying medical expertise. Depending on the circumstances they are also teacher, counselor, and friend. Interestingly, most of this work – which is real work – is ad hoc and invisible, woven into the fabric of clinician life.

On any clinic day, a physician’s time is mostly spent reviewing patient records, preparing for visits (often by discussing the cases with the team), developing treatment plans, seeing patients, consulting with other specialists on the phone, communicating with other specialists who provide services to the team’s patients, signing orders, and doing documentation work. There is a certain, slightly monotone, rhythm to the work. As patients arrive one after another, the physician goes through the motions over and over again for each patient. Whereas the rhythm of the work seems relatively repetitious from the outside, the work itself is demanding and manifold because each patient case is unique and some are quite complex. A physician’s clinic may last the whole day (often until 4pm and sometimes longer), although some days are shorter depending on patient load. Given the high demands of transplant care, on average a physician spends anywhere between 15 to 30 minutes to an hour or more – in the room – with each patient. On busy days upwards of 15 patients may come for visits. These days are crunched with very little time between each visit. The same goes for the physician’s team members.

The clinic currently has five extenders, although staffing has varied over the study period. As described earlier, extenders work very closely with the physicians and are heavily involved in post-transplant patient care.¹⁴ They are very knowledgeable about transplant

¹⁴ Extenders are not involved in the care process in the pre-transplant period.

related issues and the details of individual patient cases. While a traditional hierarchy exists in terms of the work itself – with the physicians overseeing patient care – the actual relationships between clinic staff do not reflect the hierarchy on the more personal level. Regardless of their particular role in the clinic, all clinicians address each other informally and share stories from their lives in the teamroom. In the work itself the physicians rely on their team members significantly, and trust and actively seek their opinions.

The extenders follow the cases of their patients very closely and at clinic visits usually see them first by themselves and later with the physician. Before each patient visit, an extender reviews the latest *progress note* – notes from the last visit – on the patient from the EHR, as well as the latest laboratory results and the results of any other tests or procedures. Upon arrival at the clinic, the patient is asked to go over the most recent medication list to check off which ones are currently being taken. After recording vital signs and other information such as the patient’s weight, an MA delivers this information and the updated medication list to the teamroom. Sometimes the team nurse will then see the patient first, at other times the extender may directly see the patient. Having the information from the latest progress notes, lab/test results, the medication list and vital signs, the extender probes the patient and caregiver for information on what has happened with the patient since the last visit. The extender notes what information is particularly important for the physician to know, and returns to the teamroom to discuss the case with the physician. This conversation often tends to be a discussion, albeit a rather quick one, as opposed to a one-way report from extender to physician. When the two of them leave the teamroom to go see the patient together, they usually have a tentative plan regarding any changes to the patient’s treatment. The physician may re-adjust the plan based on new or additional information that emerges during his visit or his physical examination of the patient. Once his part is complete the physician heads back to the teamroom, while the extender usually stays behind to answer any additional questions, provide additional instructions, and generally close out the visit. Extenders tend to complete much of the information work done in the EHR system while they are in the room with the patient (such as scheduling labs or typing up patient instructions), but they also enter their own

notes on the visit into the EHR system later on. Once a visit is over the extender returns to the teamroom and may continue to work on the patient's case; for example, complete orders for the patient or do follow-up work based on the updated treatment plan. Eventually the focus shifts to the next patient visit. This cycle continues, much like the physician's, as patients arrive and leave one after another.

Besides working on patient visits, the extenders follow the updates concerning their team's patients. They track laboratory, procedure, and imaging results, as well as progress notes, notes from other specialists, and correspondence concerning a patient, as these come up in the EHR system. They alert the physician to any outstanding issue and follow-up with the patient if necessary. Hence, the extenders are on top of the latest updates regarding their patients. These types of work happen in the teamroom, in-between patient visits. Close proximity allows for fast and easy communication and coordination between extender, physician, and nurse. Extenders also complete orders (although the physician's signature is required for some medications, such as narcotics). During the weeks that the physician is on inpatient duty, the extenders on the team may see some patients instead, consulting with the physician as needed. This also goes for the times the physician is out of town, and some follow-up visits on days the physician is normally not on clinic duty. Again, although a decision and responsibility hierarchy exists in the clinic, extenders are very knowledgeable, heavily involved in the care process, and have considerable autonomy. In addition to their team responsibilities, they also perform procedures such as bone marrow biopsies.

In the first 100 days post-transplant, the team nurse does not see the patient at clinic visits, but she handles phone encounters with the patient and caregiver. Once the patient reaches day 100, the team nurse gets more directly involved in patient care at visits. If the team nurse sees the patient during a visit, she does so usually before the extender and/or the physician. She reconciles medications (i.e. reviews the most recent medication list in the EHR with the patient and/or caregiver, since many caregivers take it upon themselves to manage medications) and records the changes. She also finds out which medications need refills and ensures that these orders are completed. Additionally, the nurse probes

the patient and caregiver for updates. If she is aware of a specific issue, she asks about changes or new symptoms. Once her part of the visit is over, the nurse debriefs the extender and/or physician in the teamroom. If it turns out that the patient needs a transfusion, the team nurse will help with the transfusion order as well. She also fills out any disability paperwork for the patient as needed.

As mentioned previously, one of the major responsibilities of team nurses is to manage phone encounters with patients and caregivers. Patients and caregivers are repeatedly encouraged by their BMT clinicians to call the clinic if they begin to show any symptoms (e.g. a rash, cough, shortness of breath, fever above 100.4°F, diarrhea, and so on) – “if anything unusual comes up” – or if they have any questions. As an extender sometimes puts it, “when in doubt, call.” In a phone encounter, the nurse assesses the reason for the call and either responds directly or first consults with the extender or the physician. There might be back and forth communication – face-to-face, via phone, or by messaging through the EHR – with the extender or physician before a decision is made regarding the reason for the call. The nurse documents her communications with the patient or caregiver and the responses of the extender or physician as a *phone encounter* in the EHR system.¹⁵ Patients call the clinic for many reasons: to report changes or new symptoms (e.g. an emerging cough, worsening fatigue), to ask questions about medications (e.g. what should I take for a headache?), to learn about updates (e.g. test results), to confirm information (e.g. the prescription is not at the pharmacy, did you send it already?), to get feedback on what to do or what to avoid (e.g. my caregiver has a cold, what should we do?), and so on.

Nurses have their own techniques for addressing patient questions effectively. For example, a nurse told me that patients often ask her what they are allowed to eat, because they stay on restrictive diets for a long time to prevent infections and/or due to GVHD. The nurse explained that it is more effective to ask the patients what they like or want to

¹⁵ The team nurse also manages phone encounters on days the physician is not on clinic duty. On these days the nurse works in the staff workroom at the clinic instead of the teamroom.

eat – instead of giving them generic lists on the phone – and then to let them know which of the items they can actually have. This is more effective also because all patients I have encountered have complained of the fact that food doesn't taste anything like food, especially in the first few months post-transplant. Most patients farther out from transplant report that it took a while for them “to get their taste buds back” or to get their appetite back in general. Most food items don't taste good, patients do not feel like eating anything, and consequently there can be unwanted weight loss that can exacerbate the already significant fatigue. Therefore, if a particular food item tastes relatively good and the patient is actually allowed to have it, it is a win-win situation.

It should be noted that all BMT clinicians – nurses, extenders, and physicians – also do a lot of emotion work: listening to concerns, reassuring patients and caregivers, and providing empathy and emotional support. Clinicians develop strong relationships with patients and caregivers over the lengthy transplant process. This makes it challenging for them when a patient's condition deteriorates or if the patient has to move to hospice. Two of the nurses told me that emotional aspects such as these are the most difficult part of their job. After a particularly difficult visit where the patient and caregiver were informed of disease relapse and the fact that the patient likely has weeks or months to live, an extender confided, “Sometimes you go to the bathroom and cry a little, and then you get back to work.” In fact, on two separate occasions I have seen a nurse and an extender tear up in the teamroom upon receiving news of an unexpected death. A patient who at one point received bad news from a physician recalled that although the news was actually unexpected it was obvious the minute the physician walked into the room that something was amiss, because it showed on the physician's face, who – the patient noted – “takes it all very personally.” These are all evidence for the close relationships clinicians build with patients and caregivers over an extended period of time, their dedication, as well as the emotional strain of their line of work.

5.5. Patient Experiences

It could be said that the journey of a bone marrow transplant patient begins with the events leading up to a disease diagnosis. In recounting their stories, one of the first things patients and caregivers recall is how the patients started to feel unwell. In many of the cases I observed, the onset of symptoms was relatively subtle and readily attributable to other causes until further evaluation became necessary; gradually worsening fatigue, shortness of breath upon exertion, recurring infections, and bruising are among the common complaints patients had. Mr. Smith recalled the stiffness and bone pain starting from his neck and then extending all the way down to the shoulders and knees. Mrs. Isles felt so tired she had to talk herself into getting off the couch. Mr. Moore's father noticed that he was starting to look very pale. Mr. Martin became sick with infections during a family trip. In all these cases – and others – the unresolved symptoms eventually led to an appointment with a primary care physician, and a subsequent blood test. The results of the blood test initiated a crisis situation.

In Mrs. Isles' case, she received a phone call from her doctor's office the day after her blood test asking her to come in. She knew it wasn't good news. When they called back from the doctor's office a second time to ensure that she bring someone with her, she knew it was really bad. She went to the visit with a friend of hers, where she was told that she had leukemia and that an appointment had already been made for her with an oncologist. She recalled:

“And so it was like, get the news and I'm, I'm (snaps finger) at the oncologist right there. And uh, my girlfriend, they hand me the lab work and right on the bottom it says, you know, AML. Leukemia. Um, so we're sitting in the waiting room and she's like, you do know what's happening here? And I said, yeah. And I said, I have cancer. And I have leukemia. She's like, yeah, that's what it's looking like.”

Mrs. Isles' oncologist scheduled a bone marrow biopsy to confirm the diagnosis, which she had two days later – on a Thursday, she remembered. On Monday she received a phone call at work from the oncologist, who said that he had a room ready for her at the local hospital. He told her to check in. Her first response was to panic about not having completed her work. Her husband was also out of town. She wanted to postpone the

treatment. Her friend tried to convince her to no avail, until finally Mrs. Isles' boss interfered and sent her to the hospital immediately. When she arrived there with her friend the situation had still not quite sunk in yet:

“I got to the hospital with [my friend] and of course we weren't even, we weren't thinking. It's like, okay I'm going to start chemo then I get to go home. Yeah, when they took me into the hospital room and they're like, okay honey you can start unpacking your clothes, and I was like, what do you mean? You know, I didn't know I was going to have to spend the night and so that was a shock. That was when it kind of, like, hit. And then I got hit the second time, you know like when they were doing all the stuff for the NeoStar¹⁶ and, you know, so they can put everything in. Um, and that was [names physician], another doctor. He, um, came down and he's like, okay well you're going to want to get a lot of books, a lot of magazines, you're here for a while. I was like, what do you mean? And he's like; you're here for at least a month. And I was like, wow (laughs).”

Mrs. Isles (quoted above) could not imagine what the leukemia meant – how her life was immediately and radically altered – as she abruptly found herself in the hospital. The significance of the situation began to “hit” her when she was told that she could not leave and they placed a catheter in her chest. She later noted that a number of things worked to her advantage during the transplant process. First, her bosses and colleagues stepped up to the plate and covered for her at work, leaving her to focus on the treatment and her recovery without having to worry about her job. She also had a very strong support system, with her family, husband, friends, and colleagues all helping her from the very beginning.

Other patients battled different challenges. For instance, at the time of his diagnosis Mr. Jones' kids were four and two years old. He and his wife had to be separated from the children in the first few months of his recovery, and they had to arrange in-laws and friends to take care of the children during this time. Ms. Lauren was single and eventually lost her job, her main source of income. The financial difficulties she experienced overwhelmed her. Mrs. Lewis' diagnosis was linked to earlier treatment she had received for breast cancer; making this the second time she was receiving difficult news. Still, the patients and caregivers I talked with all experienced a similar shock in lieu of their

¹⁶ A type of triple lumen catheter surgically placed into a vein in the chest. A NeoStar catheter is commonly used for BMT patients.

situation. When they were told that Mr. Martin had leukemia, Mrs. Martin remembered asking their local doctor in the distress of the moment, “Do you mean that he is going to have to spend the night in the hospital?” She recalled how this was followed by an ambulance ride the next day to the hospital where the BMT clinic is located, where Mr. Martin’s chemotherapy treatment began straightaway and he remained inpatient for weeks. Indeed, all patients whose diseases were aggressive began chemotherapy in a very short period of time. It should be noted that some patients did not arrive at this point of crisis this quickly. For example, Mrs. Lewis had a form of myelodysplastic syndrome that was addressed with a medication for six years before she found herself in the intensive care unit with a very low red blood cell count.

Regardless of when it started, all patients received chemotherapy to get and sometimes to keep their diseases in remission. The specific drug regimens and number of chemotherapy cycles varied based on each patient’s particular case. They spent, on average, several weeks to a month in the hospital each time they got admitted for chemotherapy. They were generally able to leave the hospital between the cycles once their blood counts recovered enough from the chemotherapy they received. In some cases the transplant process was initiated fairly quickly in the meantime. In others it became more urgent upon disease relapse. Sooner or later the decision had to be made for transplant. When asked if it had been a difficult decision to make, most patients simply told me that it had not. The majority felt that it wasn’t even a decision – that the decision had been made for them – in the sense that it seemed their only option for an extended life. There were a few exceptions among the patients I met, who believed there indeed was a choice to make. For instance, Mr. Martin was originally hesitant because he was concerned about how his quality of life might be affected. Although his family encouraged him to get the transplant, he did not make the decision for some time. On the other hand, although he felt that the decision had almost been made for him, Mr. Douglas noted that potential complications stirred an amount of uncertainty:

“This is, it’s not an easy decision to make. And there are a lot of unknowns. You’ve seen the book the coordinators give out, with the 52-inch long list of things that can go wrong. Yeah, so would you? There’s naturally a certain amount of ambivalence about do I want

to do this and possibly, and subject myself to any one of those possible 52-inch long list of things.”

In this excerpt Mr. Douglas is referring to the patient handbook that the BMT clinic provides to patients. Besides describing the transplant process in some detail, the handbook includes information about potential complications – which are many. While Mr. Douglas stated that this information produces ambivalence, other patients I talked to almost universally commented that the information is downright scary. This caused some of them to quit reading the material, while others acknowledged that they had to be told truthful things. In addition to finding the information in the handbook “pretty scary,” Mrs. Adams said she had been concerned about the things she heard while she was in the hospital for the chemotherapy to put her disease back in remission. She recalled her reaction as follows:

“You know it’s okay to tell you the really bad stuff. But then in your mind you’re like, well that’s going to happen to me. So that was hard too, I mean I wanted to know about it but then I was like, oh crap, I hope, like, I don’t get, you know like this rash and my skin peels off. Like those are some of the, I think, what I’ve heard the worst case things where like you actually have open sores and, you know, or the whole mouth thing. I was *really* paranoid about getting that mucositis or whatever, and I got it and it was really bad. But, you know, until you get it nothing can really prepare you.” [Emphasis original.]

Mrs. Adams, quoted above, is among the patients who said she understood why the scary information had to be given to them. Still she worried about what she considered to be the worst possible complications, describing the extent of some of her fear as paranoia. In the end she did get mucositis – which causes painful ulcerations in the mouth and throat – as well as other complications she had been particularly leery about. As she notes in the excerpt above, she felt that nothing could really prepare her for the actual experience of a complication.

Besides the intimidating quality of some of the information received, all patients (and caregivers for that matter) I talked with during this study have at one point or another noted the immense information overload they experienced both at the time of diagnosis and especially prior to transplant. They all went through the pre-transplant process described earlier in this chapter, including meetings with a BMT physician, a transplant

coordinator, and a social worker. All of them received one-on-one education, as well as a copy of the patient handbook and other printed material. At the time, none of them really knew how transplant works or what exactly it involves. None of them had heard of graft-versus-host disease. None of them were aware of how long the process would take, or how much they would have to rearrange their lives. A few of the patients knew someone who had had a transplant before, but that was the extent of their knowledge.

Once the decision for transplant was made, a flurry of activities ensued: Patients completed the required cycles of their chemotherapy regimens to get or keep their diseases in remission. They spent whole days at the hospital for the various pre-transplant assessments. Those who worked tried to arrange long-term medical leave. Out-of-town patients began to look for a place to stay in the city during the first few months post-transplant. Patients – and caregivers – started thinking about accommodations for their families, such as who would take care of children in their absence. Patients with younger children tried to find ways to explain the situation to their kids; for example, Mr. Roberts agonized over what to say to his little daughter, finally telling her that there were “bad guys in daddy’s blood” and that the doctors would take care of the bad guys. Even patients with grown children struggled with this problem. Mrs. Allen recalled that her children, all married with families of their own at the time, “*really*¹⁷ struggled. They really struggled with grief and fear.” Hence, on the one hand patients tried to cope with their own fear and to reassure their loved ones. On the other hand, several of the patients made their funeral arrangements or talked about it with their families. Mrs. Lawrence, for instance, was prompted to do this following an information session at the BMT clinic:

“There were a lot of other issues too that we had to deal with, and that part of that was preparation for transplant with the information that they give you. You know, your living will and those kinds of end-of-life things. So I, you know, went and made my funeral arrangements. It was too difficult for [my husband] to go with me. So I went with a friend. I was very very weak. You know I couldn’t go, I couldn’t drive myself. You know, but I went and made my funeral arrangements, and you know did some things like that.”

¹⁷ Emphasis original.

Mrs. Lawrence, quoted above, came to transplant when her disease relapsed within the year following her diagnosis. She recalled being very weak at the time, having already gone through treatment. Still, the preparation of a living will and end-of-life considerations compelled her to make her funeral arrangements. Her husband, who diligently fulfilled all caregiver responsibilities for her, could not bring himself to go with her to help make these arrangements. In several of my interviews and conversations with patients, making funeral arrangements, putting affairs in order, and discussing the possibility of death with families emerged as undertakings prior to and even after the transplant.

Once the process was underway, most patients were anxious to get the transplant over with, while feeling nervous about it at the same time. Mrs. Adams, who came to transplant after her disease relapsed, said she was the one who pushed for having it as soon as possible. Her motivation was more personal than a fear of the returning disease:

“My remission to my transplant happened very quickly, but I pushed for that. Because I didn’t want a lot of time at home, because then I would be too used to being home and feeling normal and not realizing that I’m still not done yet. And I just wanted to get it over with, you know.”

Knowing that she would get a transplant in any case (her sibling was found to be a match for her), Mrs. Adams – quoted above – wanted to have it done as soon as possible. She did not want to fall into a routine of normalcy only to realize that she would be pulled out of it again; she wanted to be done with treatment. On the other hand, patients whose only chance for a cure is transplant also fear that the transplant will fall through. Mrs. Isles’ first donor fell through, and her transplant had to be postponed. Then her disease came back. She recalled how her BMT physician explained to her that they would not be able to move forward with the transplant unless additional treatment got the disease level into the acceptable range. She felt it was “a miracle” – to use her own words – when her “numbers” came right within the range where they could proceed.

Once admitted to the hospital for transplant, each patient had a private room on the BMT ward. In the first few days of hospitalization the patients received their conditioning

regimens. Their transplants – which took place in their own rooms via their IV catheters – followed after a day or two of rest. Although some patients noted the anti-climactic nature of the stem cell infusion, some of them did describe it as an emotional experience. For instance, Mrs. Isles had several family members and her friend in the room. They said a prayer. She recalled the transplant as eventless and how great she felt. In comparison, Mr. Martin and his caregiver could not sleep well or long the night before his transplant. Mrs. Martin said, “it felt like high drama for us with a huge feeling of relief when the actual transplant was done.” Both of them had to take a nap for several hours after it was over.

While in the hospital, the patients felt the harsh effects of the conditioning chemotherapy. Nausea, vomiting, and diarrhea were common. Appetites plummeted. Food began to taste unfavorably different. Weight loss became a concern. Fatigue began to settle in. Mr. Martin, who had previously tolerated many rounds of chemotherapy very well, felt quite sick. Mrs. Lewis recalled feeling very weak, among other things, but forcing herself to take a shower everyday because she had read in the patient handbook that this was important. Mrs. Adams remembered getting the terrible mucositis¹⁸ she had been so afraid of, despite deliberately overdoing the mouth care routine to help prevent it. The patients were instructed by the inpatient team not to stay in bed the whole day, but to walk in the hallway or at least sit in a chair in their rooms. Patients recalled trying to walk as much as possible, wearing a mask and pushing along their IV polls. Mrs. Adams remembered deliberately avoiding other patients:

“When I was inpatient, like I would walk. You know, you had to walk everyday. And I would see people and you’d say hi. But I never really talked to anybody because I felt like I really didn’t want to know what was going on with anybody else. I only wanted to worry about myself, and what I was dealing with. And I didn’t want to hear like any other sad stuff from other people. Does that make sense? You know, I just wanted to, wanted to keep the level of getting upset (gets emotional). No don’t worry! I get like this. No, I get like this. I was like this before; I was a really emotional person. It didn’t mean I wasn’t dealing with it, but I didn’t feel the need to like go and talk to different people. And then plus, like I said when you walk, a lot of people don’t have, don’t cover their windows or didn’t have curtains. And you know, and you see them and they look way sicker. So I’m just like, I’m just, just focus on me and what’s going on with me, you know.”

¹⁸ Inflammation of the mucosal lining of the digestive tract, which causes painful ulcerations in the mouth and throat.

In the excerpt above, Mrs. Adams recalls trying to deal with her situation while in the hospital. At the time she felt the need to control her level of distress by focusing on what was going on with herself. She already had a lot to cope with. It was difficult for her to see other patients looking quite sick on top of this, so she tried to avoid further sadness by choosing not to know what was going on with them. Later in her interview, Mrs. Adams also recounted how once she was not allowed into the patient-family lounge because she had tested positive for a bacterial infection. To safeguard others from infection she could not socialize, although she did not show any symptoms of the infection at the time, and she had to wear a disposable medical gown for her walks in the hallway until she was cleared of this precaution. This experience of hers is familiar to other patients who have tested positive for an infectious agent during an inpatient stay. In all, although the patients did occasionally socialize in the hallways, in the patient-family lounge or at support groups held for them on the unit, for the most part their hospitalizations were experienced as isolation from others, both from fellow patients and the outside world. During their stay they dealt with side effects from chemotherapy, battled food intake, slept most of the time, watched television or occupied themselves on their tablet computers, and walked the hallway whenever they could. This went on for weeks. Everyday they would be told their blood counts as they waited for engraftment.

Several patients recalled significant bone pain with engraftment. Some of them did not initially associate the two until a clinician explained the connection. Upon confirmation of engraftment and hospital discharge, Mr. Martin looked forward to getting a good night's sleep at the apartment he and his wife had rented in the city. He felt extremely fatigued, and fell asleep in a recliner almost immediately after he got to the apartment. While Mr. Martin had looked forward to leaving the hospital, Mrs. Adams recalled her initial reluctance to leave when she was cleared for discharge:

“So it was a lot quicker than I thought and I, I felt, at that time my mucositis was really bad. And I felt like complete crap, and I was kind of like, wow, I was kind of worried about going home. And they said, well do you want to stay another day? And then that next day I said, well okay. I guess I'm alright. But yeah, I was pretty paranoid because I felt like, wow, I just feel like crap you know.”

Mrs. Adams' worry about leaving the safety of the hospital is a relatively common experience among patients, and not necessarily limited to their transplant hospitalizations. Upon being discharged following her transplant, Mrs. Lewis remembered thinking, "how am I ever going to make it?" She felt very weak. Throughout his many years of transplant experience, Mr. Martin wanted to avoid being hospitalized or going to clinic visits unless absolutely necessary, but there were times he also wanted to stay close to the hospital. For instance, when his wife proposed an overnight trip to their home several months out of transplant while they were still living in the rented apartment close to the BMT clinic, he suggested that they go only for a few hours instead. He felt they should stay close to the hospital for safety. Mrs. Isles said she was scared to go home after an infection and a particularly bad bout of GVHD several months into her transplant. Mrs. Scott, whose husband is a transplant patient, got nervous later in the process as the interval between clinic visits increased; she would literally count the days to when they would next see their BMT physician, fearing that something would happen in the interim.

Once discharged from the hospital following engraftment, the patients began clinic visits with their BMT physicians immediately. Initially they went for visits several times a week. On these days they would get to the hospital an hour before their appointments for blood draws, then wait for their visits. The visits generally took a long time because of IV infusions, and sometimes due to wait times to see the clinicians. Mrs. Martin noted how their time, in general, was organized according to their clinic schedule and the demands of patient care, such as the lengthy magnesium infusions Mr. Martin would get at home. She commented that both of them – both retired – "have remembered how great it feels to have the weekend arrive," where they could be on their "own schedule." Some clinic days were simply exhausting to them, and Mr. Martin was already feeling discouraged at times due to his lack of energy. In fact, in my conversations and interviews with patients, as well as in visits with their BMT clinicians, the patients unanimously commented on the extreme level of fatigue they felt in these initial months post-transplant. Mrs. Adams recalled:

"I came here for my very first appointment the week that I got discharged. And that was the first time I met [the extender]. And, you know, [the extender] was just like, oooh, you

know, you don't seem like [you're feeling well]. You know, and I'm like, well I just got discharged (laughs) like two days ago, and yeah I feel like complete crap. And then the first time I saw [my BMT physician] the following week, [the physician] was like oh, you know, you seem really down. I'm like, cause I really feel like crap.”

While her BMT clinicians noted that Mrs. Adams was feeling unwell and probed further to see whether anything else was amiss, Mrs. Martin noted that her husband would sleep for most of the day. Sleeping is the one thing Mrs. Allen could recall from the first few months following hospital discharge as well:

“I just, I slept. I bet I slept twenty hours a day at least, if not a little bit more. And I was so cold (laughs), my poor husband. We had the heat on eighty five. He walked around in his T-shirt and shorts and I just would be under blankets and shiver. So I just slept. Just slept, that's all I did, that's all I remember, was sleeping. I think I might have done a couple loads of laundry while we were at the apartment. Yeah, that's about it. Maybe made myself (laughs) a bowl of cereal.”

When asked how they would spend their days, all of the patients said they would just stay at home and do nothing, mostly because of the fatigue. None of them had experienced anything like it before, and it was perplexing to them. At the clinic visits I observed, the fatigue was the most common issue raised by all patients in the first few months post-transplant. It was a major cause of discouragement and confusion, which the clinicians tried to address visit after visit with the same patients. At the same time, the patients feared they would not get better unless they forced themselves to do things, so they would occasionally push themselves to do a little more. Mr. Davis recalled:

“Well, knowing that you had to do it, you just set your mind to do what you had to do. And so. Yeah, when I first went home it was no fun just sitting in a chair all day. Basically. I mean I got up and did a few things, but I basically sat in a chair all day long. Watch TV. Well, that was just generally, you're, you're worn out. You know, after the bone marrow transplant you just feel like they sucked everything out of you. And you just uh, I could get up, I *could* get up, and I went up and down the stairs. My bedroom is upstairs so I used to go up the stairs to go to my bedroom, you know, and come back down the stairs. So I'd do that, but at first I didn't do it very quickly. But I did it, you know. Um, so you make yourself do things because you know that if you don't, you know you're just, you're not gonna get better. You're gonna, just gonna continue to atrophy.” [Emphasis original.]

Mr. Davis tried to get up and move around a little, climb the stairs a few times, fearing that otherwise his condition might deteriorate even further. He also remembered how his wife, thinking that he was “helpless” (in Mr. Davis' interpretation), wanted to do

everything for him, which he tried to counter. He said he would go do something once his wife left the room, and then she would “have a fit” when she came back. His wife finally gave in when a BMT nurse – to whom this situation was unknown – coincidentally recommended that he climb stairs to help strengthen his muscles. Other patients made similar comments about their caregivers, families and friends wanting to do everything for them, while they knew that they had to try doing some things on their own. Sometimes they had to convince the others.

While the patients tried to cope with the extreme level of fatigue, their efforts were challenged by other changes to their bodies. For instance, all patients reported that they “lost” their taste buds; that food tasted like nothing or somewhat “metallic.”¹⁹ They were also instructed to drink several bottles of water everyday to keep their kidneys functioning normally, but they had difficulty swallowing due to the side effects of chemotherapy or they could not bring themselves to drink that much water. In Mrs. Adams’ case, her difficulty with food stemmed both from the mucositis she had and the change to her taste buds. While she couldn’t really taste the food, she strived to at least choose ones that would make her mouth feel okay. It is relatively common that patients begin to go for the texture of food rather than the taste itself. Mrs. Adams’ caregiver also pushed her to drink the recommended amount of water:

“My throat was sore, like I had [the mucositis] in my throat a little bit, and like my tongue was just so swollen. And nothing tasted like anything that you remembered. And that was the thing, it was funny because while I was in the hospital, literally up until the day I went home, my taste buds were fine. Which kind of sucked because then I got home and I was like so excited just to eat food that didn’t taste like hospital food. I mean they have some good stuff, don’t get me wrong, but when you’re here that long, and plus I’d just been here a whole month before that getting put back in remission. I’ve tried everything on the menu. So there’s nothing exciting anymore, and I got home and then everything tasted funny. I can’t, I can’t explain it, but like metallic. Or like, you know, I like macaroni and cheese. I was like, oh I can’t wait to eat, and then it tasted like just, like nothing. It tasted like nothing. And but yet you had to eat, you know. So then for me it was more about trying to eat things that, like for texture or whatever, that made my mouth feel okay... And then it was like a chore to try to force myself to drink too, because swallowing hurt so bad. So [my caregiver] everyday would take a whole bunch of water bottles, cause they told me like how many at least I should drink a day, like eight of this, the regular size ones. And so he would number them one through eight. And you know he would sit like two at a time, and he’d be like, okay by x time you have to have

¹⁹ Food tasting “metallic” was quite a common description.

those gone and, because otherwise... you know if I didn't have him pushing me on some of that stuff, that stuff I might have let go."

Based on my observations at clinic visits, drinking the recommended amount of water is among the battles caregivers commonly fight with their patients, who simply do not or cannot force themselves to drink that much water. In general, food and drink are among the top reasons patients and caregivers argue with each other in the first few months post-transplant. Mrs. Allen recounted how being able to finish a little bit of food felt like a small success, while more food on the plate felt like a big task that would never be accomplished. As her caregiver, her husband was frustrated that he could not get her to eat more while she kept losing weight:

"I was *making* myself eat for, well for a long time I wasn't doing that. And (laughs), bless my husband's heart, when we were in the apartment if I said I wanted a scrambled egg, he'd make me two and think that if there was more on my plate I'd eat more. And I'd just (wrinkles her nose). And when you're feeling like that you don't want to see big piles of anything on your plate. You want little dabs, and then if you can eat that you feel successful. But when they pile it on, you know you're never gonna be able to eat all of it, so you just kind of almost just put a little dent into it. And he just, my husband *loves* to eat, so he just could not, he just could not understand why that wasn't helping me. And then he'd get frustrated with me if I didn't eat as much as he thought I should. So he didn't understand, he's never been through anything like this. I mean he'd just go lay down and go to sleep (laughs). I did the best I could. So, and then, um, then I got to the point where I knew I needed to eat more. I mean I got down to 98 pounds. I was really very thin and I think part of the weakness was, you know, obviously from that, and um, so then I started making myself, just putting a little bit of everything on my plate and eating. When we went out to eat I ate *better*, because I didn't have to smell it and cook it." [Emphases original]

Mrs. Allen's eating was a constant topic of tension during many of her clinic visits with her husband. Her BMT team diffused the situation without taking sides. Her physician noted that she had been careful of her weight prior to transplant, while also gently prodding her by saying that he would like to make sure she has some reserve on her.

While the patients tried to cope with the extreme level of fatigue, often exacerbated by struggles with eating and drinking, most of them were also fighting various complications. Mrs. Lewis found herself back in the hospital only a week after her initial discharge. She had started vomiting and having diarrhea, which prompted her BMT physician to admit her immediately for a likely case of GVHD. The GVHD, confirmed

by biopsy, turned out to be severe enough that she was placed on NPO (i.e. nothing by mouth), receiving IV nourishment instead. She was started on high dose steroids, from which she developed diabetes. The clinicians began to check her blood sugar several times a day to manage her insulin. After not being able to eat anything for weeks, she recalled feeling very pleased when she was able to have her first Popsicle. She also recalled feeling very grateful when she had her first formed stool. Her hospital stay lasted for almost a month.

Like it was for Mrs. Lewis, complications arose quickly for Mr. Martin as well. At only his second clinic visit following transplant, his BMT physician pronounced a skin rash as GVHD, which was later confirmed by a skin biopsy. A steroid cream was prescribed to treat the rash. The clinicians noted that GVHD could also show up as diarrhea and decreased liver function. A period of “watch and wait” began. Mr. Martin did not want to have to go to the clinic until his next scheduled visit, and felt like he was “grinding” through the process. The night before his next visit the rash and the accompanying itchiness escalated. At the visit the physician declared the skin GVHD to be severe. Mr. Martin was now also reporting symptoms suggestive of GVHD in the gastrointestinal tract (i.e. GI GVHD). He was re-admitted to the hospital only about a week after his initial discharge, for further procedures to look for GI GVHD and to begin treatment with steroids. The biopsy confirmed GI GVHD, though not severe. A dietitian placed Mr. Martin on a GVHD level-1 diet with limitations to the kinds of food he could have. While GVHD issues (both skin and GI) were being addressed by steroid treatment, and ECP therapy as well, Mr. Martin developed an infection. The best-case scenario for when he could be discharged from the hospital kept changing, getting postponed to later dates. In all, he stayed in the hospital for about two weeks. By the time he left the hospital the steroids had caused significant muscle wasting, and walking was an effort for him.

While many of the patients I encountered got acute GVHD – skin, gut, liver, and even lung GVHD – at various levels of severity during the first few months post-transplant, not all of them had to be hospitalized for treatment. Mild forms were often addressed on an outpatient basis. On the other hand, it is important to note that not all patients got

GVHD either. Mrs. Adams, for example, called the clinic a couple of times thinking that a symptom she had might be GVHD, but she never had a confirmed incident. For instance, for a while she felt nauseated all the time, but her extender explained to her that they would not scope her for GVHD (i.e. take a biopsy) unless she really started throwing up, getting diarrhea several times a day, or kept losing significant amounts of weight. At another time she thought she developed skin GVHD, but it turned out to be neuropathy related to the chemotherapy. Mrs. Adams explained to me that she went through the first few months wondering about such incidents in part because she had been told that a mild form of GVHD would help fight off any remaining cancer cells; while she didn't necessarily look forward to getting GVHD, this made her really worried about not getting it at all. She added that at one point a nurse reassured her by saying that some patients never get any GVHD and do not have a disease relapse. Nevertheless, she diligently monitored herself for any symptoms – of GVHD or anything else – and would call the clinic whenever she had a question.

Graft-versus-host disease was only one of the many kinds of complications patients encountered in the first few months post-transplant. They had side effects from various medications (including numerous problems linked to steroid use), different types of infections, complications in some organ systems (e.g. heart problem causing chest pain, lung problem causing shortness of breath), and/or *failure to thrive*²⁰ (where they could not eat and drink sufficiently, and had difficulty keeping their weight and strength). A lot of the times patients had a combination of these issues, alongside GVHD. One issue would resolve and another one would spring up. GVHD would disappear only to flare-up again. Some of their complications led to additional hospitalizations, while their BMT clinicians tried to manage as much as they could on an outpatient basis.

Mr. Martin, for instance, had debilitating side effects from the steroids used for treating his skin and GI GVHD during his first re-hospitalization. By the time he was discharged, his muscle tone had been significantly affected; walking was a chore for him. He had lost a lot of weight. He continued to experience a low tolerance for food. He felt very weak.

²⁰ This is a diagnosis by which patients are often admitted to the hospital.

Loss of muscle tone and weakness eventually turned chronic, as he periodically became dependent on a cane or walker (depending on how well he was doing), and sometimes used a wheelchair when he had a lot of different appointments in the hospital. His BMT clinicians focused their efforts on trying to reduce the steroid dose without aggravating the ongoing skin GVHD. Mr. Martin used various creams and lotion to help with his skin. Treating the GVHD and preventing the muscles from weakening further turned into a vicious cycle. While these efforts were ongoing, Mr. Martin got two viral infections, one after another, at one point both of them occurring simultaneously. The steroids for the GVHD – which suppressed his immune system – also complicated the treatment of the infections. His BMT physician tried to prepare him by noting that recovery would be a long haul. Mr. Martin continued to have ECP treatments in part to help reduce the steroid dose. He was going to the hospital several days every week for lab tests, doctor’s visits, ECP treatments, and IV infusions to treat his infections and boost his immune system. Mrs. Martin became worried that he would fall or catch another infection. He started physical therapy to help him gain strength. In the meantime, one of the medications he was taking first caused swelling in his feet, and then mental confusion. He continued to lose weight. Kidney markers rose above the normal range. About two and a half months after his transplant, Mr. Martin was re-hospitalized for the second time due to a combination of recurring and co-occurring GVHD, infections, medication side effects, and his constant battle with weakness and loss of muscle tone. A social worker visited the couple in the hospital to help them cope emotionally. Mr. Martin’s physician also visited him, although a different physician was on inpatient service at the time. Mrs. Martin asked their physician if going home (i.e. to their actual, out-of-town home) around day 100 was still a realistic goal for them; the physician replied that it was not.

At the time, Mrs. Martin noted that the couple got discouraged by what they considered to be a backwards slide in Mr. Martin’s recovery. To her this meant that they had to readjust their thinking and focus on the positive: They were back in the hospital, but they were getting answers to problems and Mr. Martin was making some progress again. Still, she had to tell herself that the situation required them to readjust their thinking:

“Okay, if we have to readjust our thinking, we will do it. Both of us felt discouraged with [him] backsliding with his recovery to the point it was necessary to be hospitalized again. No doubt it was necessary, and in a way, it seemed good to have an answer to the side effects that he was experiencing which were caused by one of his medications. Not that everything is perfect now, but he is back on the road to making progress. They continue to fine-tune him with various IV medications and hydration. The physical therapist is working with him each day, and we have “homework exercises,” not that I would call myself his personal trainer... Okay, if we have to readjust our thinking, we will do it.”

Mr. Martin’s re-hospitalization lasted a few weeks. It turned out that he got well enough to go home, but it took several more months – and surviving several more complications – for this to happen.

Although Mr. Martin’s case turned out to be particularly difficult, many of the other patients ran into similar complications – multiple ongoing issues – that delayed their progress. Some of the complications resolved, while others eventually turned into chronic problems. Whether or not the issues ultimately resolved, the fatigue, the struggle, the setbacks, and the ups and downs were common, and a cause for disappointment and discouragement along the way. Mrs. Martin likened their experience to a roller coaster ride. Mrs. Isles recalled feeling very sick and scared after a particularly difficult hospitalization with GVHD covering eighty to ninety percent of her body and a life-threatening infection; she got emotional remembering how she felt when she woke up at home the morning after her discharge to a song called “Overcomer,” which she explained was all about overcoming hardships. She told herself that she would become an overcomer and fight to get better. She had survived disease relapse, as well as GVHD and life-threatening infections. She felt she had made it through because her clinician team had not given up on her.

Some patients, like Mr. Martin, continued to struggle with serious complications as they arrived at the day 100 timemarker. Since their conditions were not stable enough they had to continue coming for frequent clinic visits. The various restrictions – such as those on going home and driving – could not be lifted, and nor could the infection precautions be relaxed since the patients continued on higher doses of immunosuppression. On the other hand, the patients whose journeys had shown less adversity and those whose acute issues had mostly resolved eagerly anticipated the changes that would come around day 100. In

fact, visit observations revealed considerable pushback on the restrictions and precautions in place once the patients started feeling a little better. They either directly asked their clinicians whether they could do various things or they actually did things without telling the clinicians. Going out of town, driving, getting in a hot tub, going hunting, and tampering with medications were only a few of the many ways in which patients pushed boundaries. At clinic visits prior to day 100, patients often compared their current state of health and their lives to how they were prior to their transplants. Mr. Harris, for instance, mourned his loss of independence and kept asking his clinicians why the fatigue wasn't getting any better. Once he started feeling better, he began bargaining with his wife about how far he could drive the car. In general, when the patients began to feel a little better they strived even harder to get back to "normal."

While some patients still struggled with complications around the day 100 timemarker, even the patients who felt better commented on significant changes to their bodies and questioned these. Mrs. Allen recalled that when she went home after day 100 she "plateaued for a long time." She would still take morning and afternoon naps, and go to bed early in the evening. She remembered feeling like a little kid when she could drop her morning nap for the first time. Mrs. Adams noted that some chores, like cleaning the bathroom or mopping floors, were still too strenuous for her and she could not do these; however, she could start loading and unloading the dishwasher, do some laundry, and some cooking. She commented that as the Tacro dose was lowered she got less shaky and therefore less scared about cutting herself with a chopping knife. Mr. Davis started going back to church. At first he would arrive late and leave early, sitting in the back and wearing a mask. Over time he began to arrive earlier and socialize more. He also helped clean the church, but noted that he felt like he had done three to four hours of work after running a vacuum cleaner for about an hour. He likened the feeling to someone pulling a plug, with "nothing left inside." He said that the key was to sit down and rest intermittently.

As the patients progressed further into the transplant process some of their acute complications turned chronic and/or new complications of a chronic nature emerged.

Where patients had a considerable history of a complication they had developed substantial expertise in handling their situation. For example, more than a year out of transplant, Mrs. Isles' description of dealing with her skin GVHD showed that over time she learned some precautions she could take in her daily life to help prevent further irritation to her skin. She also continued active treatment with ECP and noticed the particular changes to her skin; she could tell when the GVHD was getting better and recognize fairly early when it started to come back. The recognition that it was coming back prompted interventions on her part:

“My skin's getting better though and I know that's from the ECP. Um, like, especially the spots and stuff, they're really lightening down. But like with my hands, it's kind of coming back a little bit with my hands. But it's because I haven't been wearing gloves when I wash the dishes and things like that. So I have to start. But I know I have to go back to that. Just start wearing, um, cream at night. Wearing my gloves at night. Stuff like that. Um, cause they were getting better, so then I stopped. And so it's like, you know, you learn your lessons (laughs). Okay I gotta start doing that again. Um, the little things. Like I forget, like with opening bottles or things like that. I try to and then, and if I couldn't get it I just, it's my attitude. It's me. You know, like I don't give up. I'm gonna try to open it, so then it's just like irritating it more and more instead of just asking [my husband] to open the water bottle.”

On the other hand, when the GVHD was new to them the patients sometimes did not immediately realize that their symptoms were caused by it. For instance, Mrs. Lawrence attributed the pain in her joints to her efforts to remodel her kitchen. She assumed that she was having the pain because she had been bedridden for so many months and inactive for so many years following her diagnosis; she thought that the muscles and joints she hadn't been using were hurting because she had started to use them again. She found out that the pain was caused by GVHD in her joints when she went for a pre-scheduled visit with a GVHD physician. The news was devastating to her, because she had expected to be taken off immunosuppression at that particular visit, which she said would have made her feel like she wasn't a leukemia patient anymore. She said the news put her into a depression for which she sought therapy.

The patients with chronic problems often had to make considerable adjustments in their daily lives. First, the majority of the patients I encountered who were many months – and in fact years – out from transplant had not been able to return to work. Mr. Roberts,

almost five years out from transplant, was just considering returning to work part-time. He said that this was very important to him because everyone around him was working. His friends had their work lives and home lives, and he couldn't find much in common with them to talk about anymore. Mr. Douglas, who had been forced into retirement because of his transplant, found meaning in volunteer work instead. He stated that when he was working fulltime his work had been valuable to other people, but his efforts had been – in a sense – anonymous. Volunteer work helped him to see the benefit of what he was doing. Mrs. Adams went back to work, but she noticed that when she tried to complete regular hours or take on regular workloads she felt completely wiped out.

For the patients with more debilitating chronic problems, the challenge was to learn their limits and come to an acceptance about their changed lives. For instance, due to skin tightness and shortness of breath (both caused by GVHD), Mr. Jones – almost seven years out from transplant – was unable to do a lot of the things he would normally do with his kids, such as sports activities. His eyes were so affected he had trouble seeing outside in bright light. His mouth was so dry he chewed gum all the time, and he had to drink a lot of fluids to be able to swallow food. He couldn't garden or mow the lawn because he worried about infections. So he focused on what he could do: household chores, shopping, and going out to get coffee. Even with household chores he had to work within certain limitations. For instance, the skin tightness and shortness of breath did not allow him to lean down and pick stuff off the floor. He could do chores that required him to use his upper body, such as putting away things or making the bed. He tried to do stretches, which he said helped with the skin GVHD.

Besides the physical difficulties however, Mr. Jones noted – as did several other patients – that one of the challenges farther out from transplant was managing interactions with other people. He explained that this was more difficult now than in the early days of transplant, because people – including friends – do not quite understand that he is still battling significant chronic illness. Now that he looked normal on the outside, it was difficult for him to explain to others that he continued to have a compromised immune system and that he had to avoid germs:

“I think it’s harder now, much harder now than it is back then you know. Well, I mean if you don’t have hair, you know, and if you look like you’ve gone through a transplant and chemo, people are gonna be a lot more understanding. Like, you know, we tell them, hey sorry don’t breathe on me or, you know, let me wear my mask or, you know, hey wash your hands or take your shoes off when you come in the house. But *now*, you know I still have a [suppressed] immune system, and you know, I mean I look, I guess if I walked down the street I look like a normal person. You know, I don’t look like I have all these issues. So it’s harder for people to understand when you don’t look sick that you have something going on. You know, I have no idea, like you could have Crohn’s or any other type of disease. I have, you know, nobody knows. But it’s the same thing with cancer patients I think. And people with GVHD most of the time you can’t tell. And so I think it’s hard for some people to understand that. Yeah. Well you look good you should feel good, sort of thing.” [Emphasis original.]

Mr. Jones could not easily tell people, like he could when he actually looked sick, not to breathe on him, or to wash their hands, or to take off their shoes in the house. These were perplexing requests to those who had difficulty understanding his situation.

Other patients noted similar difficulties. For instance, Mrs. Adams described how people around her were surprised that she had to be so careful about her food choices. When she first went back to work, she explained to her colleagues that she was like a baby because of her new immune system. This confused a colleague who asked her whether her donor was a baby. Mrs. Adams said she had to clarify how the transplant affected her immune system. The patients even had to explain to those closest to them that they were not feeling normal, even though they looked normal. When she was more than a year out from transplant, Mrs. Allen’s children suggested that she start going to the gym again. She said she had to explain to them that she first needed to be able to get through everyday tasks, such as carrying laundry baskets, groceries, or packages. She told them that she would be “ready to kick it up a notch” when she got to the point where she could handle these tasks. In Mrs. Isles’ case, she felt that similar experiences made her more understanding of other people instead:

“You know we just don’t know where someone is. Because if I walk out, especially now, you know my hair is coming back and stuff like that, no one would know what I’ve been through or, you know, like it takes me a while to step up the stairs. Like I’m having to hold on, and you know, then I have to just take, slowly go up. And before I think I would have, you know especially if I was in a rush, [I would be] going, okay okay, you know, climb, let’s go let’s go let’s go. Now I know, you know, it makes me think. Like okay, what’s making him go slower? You know, and stuff like that. And it’s also changed my

way of when I see somebody without hair, that's bald or things like that, is sick, you know, oh poor them. Like now that I see them in a grocery store [or] something like that, it's like, no not poor them, they're surviving. That's a survivor there. And so don't pity that person, you know, be happy for them. So that part's changed cause I've been through it, so now it's kind of like I don't want people looking at me like, oh that person, oh I feel sorry for them they're sick. And it's like, no you don't under – no, I'm getting better. I'm not there. So, that's the hard part. So, and the hard part is all the changes that you're going through.”

Mrs. Isles' experience with her chronic illness made her feel more compassionate towards others, stopping her to think how exasperating actions could perhaps be due to unknown or imperceptible difficulties. Other patients experienced similar changes, noting that their illness made them more patient, more understanding, and better listeners. Mrs. Isles also noted that she doesn't “sweat the small stuff” anymore, because she had been “given a gift again.”

Among the biggest challenges BMT patients had as they moved farther along the transplant process was the realization that they would never quite be the same as they were prior to their transplants. Both clinic observations and interviews with patients suggest that, despite being warned by clinicians that they would have “a new normal” after transplant, for a long time patients strive to return to the normal that is familiar to them. One of the clinic's social workers agreed that comments regarding “returning to normal” are among the most common things she hears from patients, and a cause for concern about unrealistic expectations. In the most positive cases I observed, the patients were able to resume some activities from their previous lives, but with significant changes to what they were physically capable of doing. In other cases lives changed substantially. When asked what the most difficult part of transplant was for them, many patients – at various stages of transplant – identified the loss of independence. Some patients, like Mrs. Isles, found it hard to ask for help even for lifting something heavy off the floor because they were used to being the ones who did things for others. Many of the patients lost their jobs and became financially dependent on their families. And some patients, like Mr. Martin, developed such severe complications that it became impossible to leave them alone for safety reasons. Both Mr. Martin himself and other patients commented that they keep asking who would “babysit” them today. All these situations necessitated acceptance and adaptation, both of which were ongoing processes for BMT

patients at all stages of transplant. Starting with disease diagnosis the patients were forced to come to terms with their continually changing circumstances.

5.6. Clinician Experiences

For BMT clinicians, work on a patient case begins when the patient is first referred to the clinic by a hematology-oncology specialist. At that time the priorities of the clinicians are threefold: (1) to assess the patient for transplant eligibility, (2) to develop a treatment plan for the patient, and (3) to provide patient education for informed consent and preparation for transplant. As described earlier, assessment for transplant eligibility is multifaceted; disease status, the overall health of the patient, availability of a donor, psychosocial considerations, and caregiver support are the major components.

Developing a treatment plan, or *trajectory scheme* (Strauss et al., 1997), is primarily based on established medical protocols. These are evidence-based guidelines for the management of disease. Finally, various parts of patient education are provided during the patient's transplant consultation appointment with a BMT physician and private sessions with a transplant coordinator and a social worker.

For a patient's BMT physician, at this stage of the process one of the most important goals is to bring the patient to transplant in a timely manner to maximize the chances of success. In this case success is viewed largely in terms of overall life expectancy (i.e. long-term survival). In some cases the optimal timing for a transplant – from the medical viewpoint – can be a controversial question. For example, myelodysplastic syndromes exhibit a large range of heterogeneity; in some forms the disease may be stable for a very long time (perhaps many years), while in others the disease borders on acute myeloid leukemia and necessitates more immediate intervention. In cases where the disease is stable for a long period (re: risk of death from disease is low in the short-term), the short-term risks of transplant itself could be considered as unacceptably high. Therefore, scientific studies are done to examine the role of timing in overall survival²¹. However, it is possible to note at least two important criteria considered in all transplant cases.

²¹ For an example study for MDS patients see Alessandrino et al., 2013.

First, given the aggressive nature of the treatment, the patient must be healthy enough to endure it. This was mentioned in several of the new patient visits I observed, where the physician noted that now was the time to move forward with transplant when the patient was healthy and strong and there were no additional complications. Second, the patient's disease must be in remission. In particular, there must be no evidence of disease or less than 5% blasts (i.e. diseased cells) in the marrow. Therefore, it is essential for the patient to receive chemotherapy prior to transplant in order to get the disease into remission or to an otherwise acceptable level. The BMT physician collaborates with the patient's oncologist in managing the timing of the transplant. For instance, the patient's disease should stay in remission until all other transplant criteria are met (e.g. a donor is found, pre-assessments are completed, and so on), which sometimes means additional rounds of chemotherapy. Hence, while the BMT physician does not see the patient often in the pre-transplant period, in the background – so to speak – the concern is to get to transplant at a favorable time.

Depending on the particular case, another potential concern for BMT clinic staff in the pre-transplant period is whether or not a patient will have the necessary caregiver support for transplant. As described earlier, a social worker assesses each patient's transplant eligibility from this viewpoint. The cases are not always straightforward. Mrs. Taylor, one of the social workers, described a few examples of some challenging patient situations that she helps sort out so that a transplant can move forward. Divorce, tenuous relationships, absence of immediate family members or close friends, family or work obligations, and financial considerations can complicate the process:

“We've had a number of couples along the way where we find out in the middle of everything that, oh we were actually preparing to divorce when this all came about. Like right now I'm actually working with a man who, he just recently filed. His wife's still living at their house. His first court date is set within like two weeks after his transplant. Like, we can't, we can't send you to a courtroom. And another patient, just last week actually, that I'm assessing for an unrelated transplant. And he was like, you know my wife and I are divorcing but we're on good terms and I think she, you know, I think she said she'll do whatever. And I'm like, okay well. Cause he came alone. I usually like people to bring a caregiver. And he's like, it's okay. Well, you know, talk with her, and then I'm happy to talk with her or whatever. Sure enough he got home and called me and he said no, she's not going to do it. So then it's figuring out, okay who? So a lot of times

I'm calling family members, friends, explaining their role. You know, we've had this one man years ago that uh, he had *no* support. Like, didn't belong to any kind of anything. But then he mentioned in passing to me something about this church. I said well, why don't you just talk with them, you never know, talk with the people at your church community that you went to, they might know of something, you know. And he lived, he had to move here. He had like five different people from this church be his caregivers. Like patrons living in (the city where the clinic is located). It was amazing. It doesn't always work. But that's been a huge one, that part right there, of um, you know, if no caregiver no transplant." [Emphasis original.]

The major difficulty stems from the significant responsibilities expected of caregivers. As the social worker later explained, the formal document for caregiver agreement was developed for this reason (because the clinic had been burned so many times), so that caregivers would understand what the process involves for them and not be blindsided – and not abandon the patients once their transplants are underway. Hence, prior to transplant the BMT clinicians worry about red flags that might foreshadow trouble. However, it is not always possible to catch the red flags. Mrs. Taylor explained that sometimes patients and caregivers tell the BMT clinicians what they want to hear, or minimize issues. These issues then “blow up” during the transplant process. Even in cases where no red flags exist at the beginning it is fairly common for caregiver burden to develop over time under the overwhelming and strenuous nature of transplant. Therefore, the clinicians carefully look for warning signs – especially early in the transplant process, but also later on – to identify issues and work with the patients and caregivers to manage situations.

Another focal point for BMT clinicians in the pre-transplant period is to identify any mental health or behavioral issues that may be cause for concern later in the transplant process. A patient's social worker is also responsible for this assessment. If the patient has worked with a mental health professional before, the social worker asks the patient for a signed release to talk with that healthcare provider as well. As with caregiver support, identifying or addressing behavioral issues is not always straightforward. In one case, for instance, I was in the clinic teamroom when loud shouts were heard from down the hallway, prompting all clinicians in the teamroom to immediately rush out to help address a potential situation. The situation was that a pre-transplant patient and the caregiver were both screaming at a social worker because they had been reminded that

the patient's little kids should not accompany the patient to clinic visits after the transplant. This incident represents an unusual case, where the patient and caregiver's responses were so extreme that security guards had to be called to the floor. The patient's physician interfered to handle the situation. This was not the only issue the clinic had to address with the patient either, as a laboratory test showed that the patient also lied about substance abuse. Although this is an extreme case (and the patient was to have an autologous rather than an allogeneic transplant), I use it to show that assessing and addressing patient issues prior to transplant is no easy task. The clinicians know very little about their patients and the caregivers this early in the process, and have to rely on their honesty and cooperation to a certain extent. It takes work to identify potential concerns, and then to address these while also establishing a relationship and building trust.

Besides overall transplant eligibility, another point of concern for BMT clinicians is the patient's financial situation. The clinicians, and especially the social workers, are aware that different patients (and their families) come to transplant with a variety of financial difficulties. Some situations are uncomplicated: the patient and caregiver are both retired, have insurance, and are financially secure. In other cases, especially where patients are younger, there can be a complicated set of problems. Mrs. Taylor, the social worker, described some of the difficulties as follows:

"I've got a lot of people in their forties and fifties. They're still working, in the midst of their careers, raising kids. You know, two income families sometimes, or a stay at home mom and then the other person needs to stay working. So they have to either find someone else to be the caregiver, also find someone to continue taking care of the kids. Or the spouse has to quit working, and they're the ones that carry the insurance. I mean it's just a mess. Financially things have gotten a lot worse for our patients over the years. I've really watched that get a lot worse. Like we've had people lose their homes, downsize to an apartment, have to spend all their retirement money, you know, or go back to work too soon because if they don't they lose their job or they lose their insurance, then they're risking their health. It's a horrible thing. Like just this morning I got paged up to fill out some paperwork with one of our patients coming in because she didn't work, and her husband's got to take off work [without] pay to be her caregiver. And so they have no income that's going to be coming in and they don't have any other family support around. So that's the tough part too, cause there's not many resources out there for people."

As the social worker describes in the excerpt above, some patients and families have to navigate very challenging financial situations. Given the huge expenses associated with a transplant and the limited resources available to patients and families, it is no easy feat for the social workers to help them in this process. Financial considerations, emotional and social considerations (e.g. having to find someone to look after the kids, losing one's home or one's job), and health considerations (e.g. risking one's health in order not to lose income and insurance) are all intertwined in these situations. Accordingly, the concern that BMT clinicians have for the patients and caregivers is manifold. Whereas the social worker tends to be the one who is more aware of issues or potential issues in the early stages of a transplant, as the process unfolds repercussions trickle down to affect the BMT clinicians in various ways as well. For instance, caregiver burden, non-compliance with treatment, or depression and anxiety can surface, requiring clinician intervention.

While a patient's BMT physician and social worker are concerned with the issues outlined so far, the patient's transplant coordinator works to identify an appropriate donor match. The donor search process can be quite difficult, particularly in cases where an unrelated donor must be found. Once a patient is HLA-typed and this information is entered into the registry, potential matches are identified immediately. However, the rest of the process can be complicated. Usually the first step is to contact the donor candidates and ask them to send blood samples to the hospital for further testing. As transplant coordinators explained it to me, it is possible that some donors cannot be reached, some are no longer eligible to donate, some have changed their minds and are unwilling to donate, and some are not available to carry out the responsibilities expected of them within the timeframe necessary for the patient's transplant. I was shown an example case on the computer that showed several potential donors for a patient blocked out on the screen because they were not available or willing to donate. Even if a donor is willing and available, it is possible that further testing and examination of the donor will show that the transplant cannot proceed with this match. In these cases usually other options are considered, such as searching for an unrelated donor who is a less than perfect match

based on HLA-typing²² or looking into umbilical cord banks. Hence, a patient's transplant coordinator is concerned about identifying a good donor candidate without whom the whole process would fall through. According to transplant coordinators, from the initiation of a donor search to the patient's transplant could take a minimum of four to six weeks. This is for transplants from unrelated donors only. In comparison, the process could be completed in about two weeks if there is a sibling match.

Finally, a key priority for all BMT staff members involved in a patient's care in the pre-transplant period is the patient and caregiver's understanding of transplant, which must be sufficient for informed consent and preparations for transplant. Informed consent is at the heart of contemporary medical practice, so there is both a legal and ethical component to patient and caregiver education. On the other hand, transplant is an incredibly complex process that requires enormous amounts of work by all parties involved both to make it happen and then to effectively navigate through it. Therefore, patient education is a crucial factor. However, as I will discuss further in the next chapter, there are significant challenges to patient education particularly in the period prior to transplant despite the best efforts of BMT clinicians. The clinicians readily accept the information overload that patients and caregivers experience. They strive to counteract this in different ways. For example, Mrs. Taylor explained that she aims to both assess a patient and caregiver's level of understanding and to reinforce important points:

"I don't meet with the patients the first day like the doctors and nurses do, because patients get so overwhelmed with information already. A lot of times it works out [that] I'll talk with them days after, a week after, whatever. And then I kind of reiterate what they learned at that first appointment, talk about some of the same things. And kind of try to see what they remember, fill in what they don't. Re-explain, stuff like that. I will a lot of times do like a *basic* understanding. Because I want to get the idea, if I can let the team know, like, these guys don't seem to get what they're signing up for. So I'll just say like, did we talk with you about graft-versus-host-disease or GVH? Yeah. What do you remember about that? You know. And then I'll just give them the basic of like, yeah, you know, your body the host, the donor cells the graft. Basically I will just say we just want to know of any new symptoms early. I keep it basic. I don't go into too much medical cause I'm not the medical. And I'll say that, like I'm not the doctor, I'm not the nurse, but in general you're looking for certain symptoms and you want to let us know. The earlier the better. Instead of just telling them, I myself will say, what is your understanding of how long you will be in the hospital? How long you'll need a caregiver? How long you'll

²² Risk for complications, primarily GVHD, is higher in less than perfect matches.

have to live here? I kind of figure out where they're at with it. And it differs." [Emphasis original.]

As Mrs. Taylor notes in this excerpt, it is important for the BMT clinicians to know that the patients and caregivers have a basic understanding of what they are signing up for. In order to help them gain a better understanding, some key points are reiterated in subsequent meetings. However, the information is not merely repeated; it is first assessed and then reinforced. Still, basic understanding of the material differs from patient to patient (and caregiver to caregiver). Transplant coordinators also note this. For instance, Mrs. Mitchell – a coordinator – explained that their interactions with patients and caregivers are not limited to their in-person encounters at the clinic (e.g. at education sessions); rather, there is a lot of phone conversation with them prior to transplant. Because the coordinators are the patients' main contact person at the clinic in the pre-transplant period (and patients actually have a direct phone line to coordinators), patients and caregivers often call with questions. These questions are sometimes related to the material discussed in education sessions. However, the questions tend to pertain more to immediate concerns or practical considerations, such as housing or the duration of transplant hospitalization, rather than broader transplant-related questions. Mrs. Mitchell noted that there are still significant information gaps that become apparent when patients are admitted to the hospital for transplant. The inpatient team, she said, finds that patients – and also caregivers – do not remember much of what was reviewed with them prior to transplant.

As described earlier in this chapter, the BMT clinic is only peripherally involved in the process once a patient is admitted to the hospital for transplant. The inpatient BMT team is responsible for patient care instead. Because the field site for this study was the outpatient clinic, I am not very familiar with the experiences of the clinicians on the inpatient team. However, it is important to note the inpatient team's observation (as referenced by Mrs. Mitchell, the transplant coordinator) of information gaps that require ongoing patient and caregiver education on their part. I also observed several support group meetings that were primarily attended by patients on the ward and/or their caregivers. The social workers, both professional and in training, who facilitated these

meetings were cautious about patients and caregivers comparing their cases. This is a concern for clinicians in general because it could lead to false expectations or unnecessary fear on the part of patients or caregivers. BMT clinicians, in general, are careful to note that “no two transplants are the same;” each patient – and caregiver – will experience transplant differently. This is due to many factors, such as the type and severity of complications, co-morbidities, psychosocial issues, and social support. Each patient and caregiver’s circumstances are somewhat different. Therefore, although talking with others who are going through similar experiences can be invaluable, there is also a real danger associated with drawing direct comparisons. Social workers have observed that some patients go to a support group meeting and leave it completely demoralized if many of the people who joined the meeting happened to be quite sick. As described in the previous section of this chapter, some patients also noted this; for example, patients like Mrs. Adams deliberately avoided other patients during their hospitalizations because they did not want to be discouraged by seeing them very sick. Hence, these types of concerns are real for BMT clinicians who find that they need to manage unfounded hopes, fears, or expectations. In all of the support group meetings that I observed, the social workers addressed this issue directly and carefully by explaining the downsides of making comparisons.

The period around a patient’s hospital discharge is also a transitional period for BMT clinicians for a number of reasons. First, there is the formal handoff of patient care from the inpatient team. Second, this is the time when core team members primarily responsible for outpatient post-transplant care begin to establish relationships with patients and caregivers. These are the clinicians who care for the patients through most of the transplant process. Up until this point in transplant, a patient’s BMT physician will have seen the patient and caregiver only a few times, the last time likely being several weeks earlier.²³ While the BMT physician gets reacquainted with them, the extender(s) and nurse(s) get introduced to them. Extenders have often noted in the teamroom that a certain visit would be the first time they would get to meet a patient. These have been some of the occasions where I heard them mention that they do not yet “know” a

²³ Unless the patient’s inpatient stay overlapped with part of the physician’s inpatient rotation.

particular patient. They generally mean this both in terms of the patient's medical case and personal style. After the first visit clinicians sometimes talk about their impressions of the patient and/or caregiver with their team members. For instance, they note that the patient is very engaged or that the caregiver does most of the talking. Hence, this is the time where getting to know a patient really begins. As described earlier, this has important implications for patient care, including probing for and delivering information. Third, this is a transitional period because it involves orienting the patient and caregiver to outpatient post-transplant care. It is in these early periods that clinicians often find themselves explaining organizational practices. For example, patients learn that it is better to call the clinic early in the day to ask questions or report issues, since the clinicians can then get back to them before the clinic day is over at around 4pm. If a patient or caregiver delays calling for a potentially urgent matter, it is likely that the patient will have to go to the emergency room. This is something the BMT clinicians do not prefer either, since transplant-related complications require their expertise and immediate intervention is often crucial. Therefore, one of the goals of the clinicians at this time is to help the patient and caregiver get acclimated, which is also a part of establishing effective working relationships with them.

Particularly in the early months post-transplant (although it continues further into the process), the clinicians find themselves having to address patient concerns regarding extreme levels of fatigue, loss of taste, lack of appetite, and fear of weight loss. Based on clinic observations, these are the chief complaints from patients and caregivers at visits. Mrs. Kelly, an extender, commented that these concerns are so common and to such a degree that she spends half the visit explaining to a patient that these are the norm, what is expected after a transplant. This is also consistent with patient and caregiver accounts regarding the major issues in the early post-transplant period. It takes a very long time for the issues to improve and the worry to dissipate to an extent. The clinic nurses also get a lot of phone calls with questions regarding these concerns. These are some situations in which they use such strategies as asking a patient what she or he would like to eat – instead of providing them with generic lists of food items – so that they can let them know which ones the patient could have.

As described earlier in this chapter, in the first few months following a patient's hospital discharge a priority for BMT clinicians is to identify and treat potential complications – such as acute GVHD and infections – before these get rapidly out of control. For this they need the active cooperation of the patient and caregiver. The patient should take the prescribed medications correctly and regularly. Infection precautions should be followed carefully. Restrictions should be abided. Symptoms should be noted and reported in a timely manner. Breaking the rules, so to speak, for any reason could have dire consequences. Therefore, the clinicians become concerned whenever there is any non-compliance with treatment or uncooperative behavior. Mrs. Kelly, the extender, noted that such issues tend to be less common in the early days of transplant when patients are feeling really sick and they are aware of the gravity of their situations. Non-compliance and uncooperative behavior become more of a problem as the patients start to feel a little better. This constitutes a significant source of frustration for the clinicians who note that the patients are risking serious complications and endangering their lives by not following recommendations. For instance, patients tamper with or forget their dose of anti-rejection medication or steroids, risk infections by the activities they do, or try to reschedule their clinic visits when they actually require close follow-up.

When asked about non-compliance and uncooperative behavior, physician extenders have emphasized that the timing, the type, and the extent of such behavior really varies by patient; there is a spectrum of non-compliance. For instance, one out-of-town patient started to insist on going back home when she was merely twenty-two days out from transplant. Another patient told his clinicians at multiple visits within the first 100 days that he should be able to get into his hot tub because it's clean. A third patient – who exhibited non-compliant behavior more than once – claimed he forgot to take his Tacro and ended up getting a rash. Based on my observations at clinic visits, the clinicians begin to get even more pushback on precautions, restrictions, and even medication schedules as the patients approach the day 100 timemarker. This is the time when patients and caregivers generally expect rules to be relaxed or some restrictions to be lifted, so they ask if they can start doing things earlier or the clinicians catch them in the act of not

following recommendations. The tricky part for the clinicians is that – regardless of the day 100 timemarker – in practice they have to make decisions on a case-by-case basis. The treatment plan, precautions and restrictions are all evaluated and re-evaluated in context throughout the transplant process. Hence, in practice, around day 100 a patient's state of health and the implications are often re-assessed, re-explained, and re-negotiated.

Beyond day 100, disease relapse continues to be a possibility. The BMT clinicians worry about this possibility, especially in what they consider to be high-risk cases, as well as the emergence of chronic GVHD. If there aren't any major complications that require its continuance, a patient's BMT physician begins to taper down the Tacro dose (i.e. lower immunosuppression) around day 100. As the clinicians have noted, this is when they actually begin to get a little nervous because they don't know whether GVHD is going to emerge with reduced immunosuppression. Since the patients generally get to go home and their clinic visits are less frequent, it is more important for them to look for symptoms and notify the clinic immediately. The clinicians worry about how diligent the patients are going to be in identifying and reporting symptoms when they feel relatively better, especially since how soon an intervention is made makes a huge difference. For instance, as an extender noted, if a patient delays reporting symptoms of skin GVHD thinking that a little change or a little extra time would not make that much of a difference, the skin can start to become sclerotic (if the GVHD involves tightening in the deeper layers of the skin). Once this happens there isn't much that can be done to reverse the sclerosis. Patients generally lose range of motion and one patient had to have her fingers amputated. GVHD of the lungs and liver, and any infection (since a patient is still immunocompromised though the medication is gradually being lowered) can also become life threatening if intervention is delayed. Therefore, whereas many patients tend to feel better and are able to do more, the clinicians have particular concerns regarding the period beyond day 100. In order to get a baseline assessment of chronic GVHD, to reeducate patients and to re-sensitize them to the importance of self-assessment and timely reporting of symptoms, allo transplant patients are generally seen by one of the GVHD clinics around six months after their transplants. Patients are referred for an assessment and consult sooner if significant chronic issues arise; however, a patient's

BMT physician continues to oversee the treatment in the chronic period, including the treatment of GVHD in collaboration with one of the chronic GVHD clinics.

Physician extenders have noted that one of the major difficulties for patients as they get farther along the transplant process is having to cope with one complication after another; as one issue resolves a different one emerges, leading to what Mrs. Martin, a caregiver, described as a roller-coaster ride. The process turns into this prolonged struggle that wears patients and caregivers out. They begin to feel that recovery is taking too long and start asking questions such as why they are not getting better or when they are going to get better. The clinicians try to help them through these struggles, but they do not always have the answers. It is not possible to know whether another complication will arise, or when the next flare-up will be. Therefore, the clinicians play an important role in helping a patient through processes of acceptance and adaptation that run parallel to the treatment process. For instance, at clinic visits I observed patients ask their clinicians if their current state of health would be “as good as it gets.” In some cases the answer was yes, such as when a patient’s skin sclerosis or loss of lung capacity was not expected to improve. In these cases the clinicians tried to help the patients in two ways: by confirming that their chronic issues or disabilities were permanent, and by talking to them about ways in which they might manage their situations better and prevent further deterioration. Where a patient’s situation might in fact improve the clinicians made sure to note this. Hence, the clinicians continue to do a lot of emotion work in later periods of transplant.

From the perspective of BMT clinicians, one of the major challenges in the period beyond day 100 is to begin partially transitioning patient care to primary care physicians and/or oncologists. When asked about the difficulties they have with patients farther out from transplant, the BMT clinicians almost unanimously identified this as a major struggle. I dedicate a subsequent chapter to the challenges with this transition. In general, BMT clinicians want patients to re-establish contact with their primary care and oncologists for issues unrelated to transplant and general follow-up. As detailed later, the transition constitutes difficulties for all parties involved: the BMT clinicians, patients and

caregivers, as well as the physicians to whom care is transitioned. Patients and caregivers tend to be extremely reluctant to shift some of their care to other practitioners for various reasons. As a patient's condition begins to stabilize, it is usually a struggle for BMT clinicians to persuade the patient – and caregiver – to follow-up with their primary care physician and oncologist instead.

Chapter 6

Temporal Alignment and Information Work

In this chapter, my aim is to show that BMT patients and caregivers experience and envision time – and consequently the transplant process – fundamentally differently from BMT clinicians. Misalignments between the different perspectives constitute points at which particular issues related to information work arise. In the following sections I first describe temporalities as experienced and utilized by these two broad groups of participants in the transplant process, then I illustrate misalignments and implications for information work using specific examples.

6.1. Clinician Time

Time as envisioned and enacted by BMT clinicians is a composite of multiple underlying temporalities. My aim in this section is to describe and unpack some of the major temporal structures that guide their work throughout the transplant process.

6.1.1. Temporalities Associated with Diseases, Treatments, and the Human Body

By virtue of their training and the subject matter of their profession, the temporal elements that are the most influential in guiding the work of BMT clinicians are those associated with the diseases they treat and the interventions involved in the transplant process. Additionally, temporalities associated with the human body and each patient's bodily responses to illness and interventions play equally important roles.

BMT clinicians are in effect the chief managers of a transplant patient's illness trajectory (Strauss et al., 1997), the associated activities, events, and occurrences of which have a structured timeliness (Reddy et al., 2006). An illness trajectory is primarily driven by the nature of the diseases a patient has and the interventions used against these. Diseases progress and regress at different rates; they can be of aggressive or indolent forms. Diseases that necessitate a bone marrow transplant vary in nature considerably. For example, some acute forms of leukemia are very aggressive. Some myelodysplastic

syndromes (MDS) progress slowly over many years. On the other hand, some forms of MDS progress quite rapidly and evolve into leukemia. Disease diagnosis and subtyping therefore constitute the crucial starting point in managing an illness trajectory and set in motion a certain sequence of interventions based on established medical standards and protocols. Similarly, other diseases that arise in the transplant trajectory of a patient – such as acute or chronic GVHD, or different kinds of infections – have their own temporal features. Acute GVHD usually emerges within the first few months post-transplant, and is a “quick and angry” type of disease (as characterized by BMT clinicians). Chronic GVHD tends to emerge later and is rather stealthy in nature (again, as characterized by BMT clinicians). Everything from a viral infection to fungal pneumonia that may emerge as complications in the process has anticipated temporalities associated with them.

The BMT clinicians’ knowledge of the temporalities that underlie particular diseases constitutes the guiding principles of treatment, and structures how they envision the transplant process. For instance, at the beginning of a patient’s transplant trajectory the nature of the disease is among the most important factors that influence a BMT physician’s preferred timing for the transplant. As described in the previous chapter, for a potentially successful bone marrow transplant the underlying disease should be in remission, or there should be less than 5% blasts (i.e. diseased cells) in the marrow. Where relapse risk is higher – or the disease is known to be aggressive – it is critical to do the transplant as soon as possible. Hence, the perceived urgency for transplant prompts downstream activities in the process accordingly. In the post-transplant period, the knowledge of the temporalities associated with acute and chronic GVHD helps to structure clinical oversight as well as interventions. Clinical follow-up is more frequent in the first few months so that the clinicians can prevent, as well as identify and treat acute complications as soon as possible. In fact, this is precisely the reason why patients and caregivers are required to live within a fixed distance – in miles – from the hospital in the first few months; interventions for acute complications must be made quickly. The knowledge of the temporal features of acute GVHD also affects treatment decisions. For example, as described earlier, in the first few months post-transplant a BMT patient is on

higher-dose Tacro (i.e. the anti-rejection medication), which leeches magnesium from the patient's body. The patient self-administers IV infusions of magnesium daily (which is quite inconvenient at first since it takes about six hours to complete) and is gradually transitioned to magnesium pills. The transition is generally completed around day 100. One factor that the BMT clinicians consider is that both acute GVHD of the lower gastrointestinal tract and magnesium pills (but not IV magnesium) tend to cause diarrhea. The timing of interventions (transition to magnesium pills) and symptoms (diarrhea) are therefore managed and followed to prevent misattribution of the symptom. Similarly, in the period beyond day 100, the BMT clinicians diligently look for symptoms of chronic GVHD as the immunosuppression is gradually tapered. Hence, symptoms that patients might attribute to other causes (such as thinking that joint pain is from using muscles and joints that haven't been used much, or shortness of breath is from deconditioning) alert the BMT clinicians to the possibility of GVHD. Therefore, knowledge of *disease time* is crucial for the work of the clinicians and how they envision the temporal trajectory of transplant.

The diagnosis of a disease triggers treatment based on standards of practice and established medical protocols. Protocols are evidence-based guidelines (based on scientific studies) that describe an organized approach to treatment. The various interventions that follow from standards and protocols all have their own pace and rhythm; for instance, the precise regimen and cycles of chemotherapy, duration of high-dose immunosuppression, timing of medication tapers, and so on. Therefore, it is important to distinguish temporalities associated with treatments – or *treatment time* – from those associated with the nature of diseases. For instance, every medication has its own kinetics. In fact, a whole scientific field – pharmacokinetics – is dedicated to the study of how drugs are absorbed, distributed, and eliminated from the body. These studies help to determine the onset, duration and intensity of a certain drug's effect and to define dosing intervals. A clinician's general knowledge of these both directs the management of illness and helps to envision its temporal trajectory. For example, it usually takes a few weeks to see the effects of antidepressant drugs. At a clinic visit, Mr. Parker's BMT physician explained this to him as he was just going on an antidepressant

for the first time. The physician noted this information in particular to preclude doubts about the efficacy of the medication in the upcoming days, telling Mr. Parker that they would “give it time to work.” This approach helps to gain patient trust (trust in the treatment and in the physician), as well as to ensure that the patient does not feel discouraged by seemingly persistent symptoms.

In getting a patient’s disease into remission and the transplant process that follows, treatment time has a great influence on clinician work and the temporal trajectory of transplant. For instance, chemotherapy regimens are administered in a precisely timed manner to get optimal effect. Protocols describe what combination of chemotherapy drugs should be given and on which day of treatment, as well as the particular timing and duration of treatment. In one common protocol called 7+3, which is used for getting acute myeloid leukemia into remission (this is called *induction* chemotherapy), one drug is given as a continuous IV infusion over seven consecutive days, and another drug is given daily as IV injections in the first three days of treatment. So the administration of the regimen lasts a total of one week, but clinicians keep a patient in the hospital a few weeks longer. This is because as the drugs show their effect the cells in the bone marrow are destroyed, leading to low blood counts. In about a week to ten days the patient enters a transfusion-dependent period (i.e. dependence on red blood cell and platelet transfusions) with low immunity. A bone marrow biopsy is done in about two weeks from the initiation of chemotherapy to evaluate the presence of disease in the marrow, which decides whether or not the patient will receive more chemotherapy (called *reinduction*) to try to get the disease into remission. In general, the patient is discharged from the hospital once blood counts recover enough from the chemotherapy. This takes on average two to three weeks, but varies by patient. Hence, unless there is need for reinduction, the patient is in the hospital for a total of three weeks to a month. If remission follows from this treatment it is possible to proceed with transplant. In some cases additional cycles of chemotherapy (called *consolidation*) follow induction. These have similar temporalities associated with them. The approximate timing of a transplant can therefore be determined, and other activities associated with the pre-transplant period accordingly scheduled.

Similar temporalities as with the chemotherapy regimen described above (to get the disease into remission) are associated with the conditioning chemotherapy that precedes transplant. The conditioning regimen is precisely defined and timed, as is the transplant itself that follows. For example, there is commonly a day or two of “rest” (i.e. no treatment) between conditioning therapy and transplant to allow for the chemotherapy to be cleared from the body before the new stem cells are infused. Other medications are also carefully timed. For instance, anti-rejection medication is usually started a few days prior to transplant so that it is in effect when the donor stem cells are given. Medications in the prophylactic regimen are initiated on particular days: usually, the antifungal on hospital admittance, the antiviral on day 0, and the antibacterial on day 1 of transplant.

In the post-transplant period, temporalities associated with treatment continue to influence the temporal trajectory of a transplant in fundamental ways. As is generally the case, these are closely linked to disease time. For instance, Tacro taper usually begins around day 100, when the risk of acute GVHD decreases as well. The taper plays a central role in the illness trajectory; immunosuppression is reduced (a positive change from the perspective of infection risk) but it is possible that chronic GVHD will begin to emerge. A little chronic GVHD can be preferred to keep the disease at bay (i.e. to get the graft-versus-disease effect). The taper itself follows standards of practice with regards to temporal schedule, with dose reduction every two to four weeks. In the absence of any complicating factors a patient could be off Tacro by the six-month anniversary of transplant. However, as the BMT clinicians note, this does not happen very often. They rather adjust the tapers based on a patient’s particular situation. Similarly, if a patient is on steroids the steroid taper follows standards with respect to temporal schedule. If steroids are used for acute GVHD the taper can generally go faster (e.g. weekly tapers); however, once lower doses are reached the taper slows down. On the other hand, if steroids are used for chronic GVHD the taper is generally slower overall (e.g. every two to four weeks). Other examples of treatment time include the gradual transition from IV to oral magnesium in the first few months post-transplant, and a monthly treatment with

an aerosolized drug (Pentamidine) as prophylaxis for a particular type of pneumonia (called PCP pneumonia) that starts on day 30 post-transplant.

As already implied in the descriptions above, a third category of temporality that is in practice closely related to disease and treatment-related temporalities is associated with a *patient's body and its responses to treatments and diseases*. A body's recovery from chemotherapy, the engraftment of donor stem cells, and a body's adjustment to or from various medications are all examples. One example that comes up frequently in the post-transplant period relates to steroid tapers. At clinic visits, the BMT clinicians are careful to forewarn the patients being tapered off steroids that they may begin to feel more tired following the tapers, particularly at lower doses. The clinicians explain that "a little tired is okay," but if there is a significant change then the rate of the taper could be adjusted "to give your body time to catch up." A patient's body needs time to "catch up" because it has been getting steroids externally for some time and has to re-adjust to making a sufficient amount of steroids on its own (the condition is called *adrenal insufficiency*). The clinicians then instruct the patient on how to adjust the taper if needed. For example, instead of taking 15mg of the steroid everyday, a patient may go back up to 15 and 20mg on alternating days to slow down the taper. Similarly, antidepressants should not be stopped cold turkey either. The appropriate tapering schedule for an antidepressant is generally adjusted by how a patient responds to each dose reduction. Finally, responses to treatment are not necessarily limited to medication therapies. For instance, a patient's body may respond to physical and/or occupational therapy over time. Several of the patients whose visits I observed were prescribed therapy over various periods of time. A key consideration for BMT clinicians is that different patients' bodies can respond differently to the same treatments. Learning about each patient's responses is an important part of getting to know patients, and the knowledge factors into the management of a transplant trajectory.

As a patient's transplant trajectory unfolds, a key priority for BMT clinicians is to favorably align temporalities associated with diseases, treatments, and responses to treatments for the various interventions to be effective. The timing from remission to

transplant, the starting point of anti-rejection therapy, the duration of immunosuppression to prevent or treat GVHD, the duration of antibiotic treatments to address active infections, and steroid tapers to effectively manage adrenal insufficiency are all examples of such alignments. In effect, based on their knowledge of these different temporalities in this particular clinical context, BMT clinicians are able to envision the temporal trajectory of illness. In pre-transplant education by BMT clinicians of various roles, the patients and caregivers are provided with a bird's eye view of transplant based on this knowledge. For instance, a patient is given the precise schedule for the chemotherapy regimen, the likely duration of transplant hospitalization, the day 100 timemarker for the broad separation of acute and chronic periods, and the one-year anniversary of transplant as the time by which the patient may be off immunosuppression (although six-months is the ideal scenario, it is relatively rare). Based on the likely course of acute GVHD and the Tacro taper, and because it is possible that acute issues will resolve and the patient's condition will become more stable, day 100 post-transplant is also associated with the lifting of certain restrictions and relaxation of certain precautions.

In the new patient as well as return visits I observed, BMT clinicians sometimes used language such as “in the best case scenario” to indicate that the bird's eye view of the process is more of an ideal course for transplant. In practice, the clinicians know that each transplant's trajectory may – and very likely will – unfold differently for various reasons, some of which are related to diseases, treatments, and bodily responses. Where a BMT clinician can anticipate a different course than the best-case scenario, it is possible to adjust patient and caregiver expectations to a degree. For instance, in one case a BMT physician noted that there was higher risk of late-onset acute GVHD because of the particular conditioning regimen that the patient received. In another case the BMT physician tapered the immunosuppression slower because the patient had aplastic anemia, which is a nonmalignant disease, and therefore there would be no benefit from any graft-versus-disease effect as in cancers (i.e. better to avoid any GVHD, hence the slower taper of immunosuppressive medication). On the other hand, the clinicians cannot realistically predict everything that might happen to a patient following transplant. Multiple and/or challenging complications may arise that delay progress in recovery. Furthermore,

besides factors associated with diseases, treatments, and bodily responses, there are also more personal considerations that affect the temporal trajectory of transplant as reflected onto a patient's experience of it.

6.1.2. Adjustment of Temporal Markers Based on Personal Considerations

As described in the previous section, BMT clinicians envision the broad temporal trajectory of a transplant predominantly based on their knowledge of the temporalities associated with the underlying medical conditions and corresponding treatments. In practice, these temporalities are generally estimated in terms of Newtonian linear time, and are rooted in scientific studies and observations. For instance, studies have shown that risk of disease relapse is higher in the first 100 days post-transplant, and also that it drops significantly beyond the first year anniversary of transplant. Studies have shown that engraftment usually takes two to four weeks, and so on. Based on these a particular trajectory may be anticipated. Associated with this are treatment schedules and the various precautions and restrictions superimposed on the temporal trajectory of recovery. However, in practice this trajectory serves as a framework that is actively adjusted for each patient by the BMT clinicians in context according to both medical and more personalized considerations.

Non-medical considerations generally pertain to the BMT clinicians' knowledge of their patients at a more personal level, and their familiarity with the patients' particular life circumstances. This knowledge is built over time based on personal observation and interaction. For instance, the trust that the clinicians have in a patient and/or caregiver regarding how well they manage patient care influences decision-making on close clinical oversight. At several clinic visits I observed, the patients were allowed to decrease the frequency of visits to the clinic because the clinicians trusted that the patients would call and report symptoms honestly and in a timely manner. Particular life circumstances, such as the financial situation or caregiver situation of a patient, also prompt adjustments to the temporal trajectory of anticipated changes. For example, a non-local patient who had difficulty affording a rented place close to the hospital was

allowed to go home sooner than when the clinicians thought would be ideal. A different patient two months out of transplant was cleared to be left alone by the caregiver a few hours at a time due to the caregiver's other obligations, as long as the patient had "lots of back-up to call" if needed (as instructed by his physician extender) and "stuck to watching baseball" (i.e. did nothing dangerous, as instructed by his BMT physician).

Clinic observations and interviews show that the BMT clinicians respect the explicit preferences and wishes of their patients and the caregivers, and try to accommodate these within acceptable safety measures. Most BMT patients and caregivers tend not to be passive recipients of healthcare; they openly state their thoughts and feelings concerning various issues, and often try to collaborate – or rather negotiate – with their clinicians to navigate the process more comfortably and effectively. In some cases the clinicians do not find it safe to grant the wishes of the patients. For instance, Mr. Roberts – who was past the standard period of driving restriction – got into a minor car accident that could not immediately be linked to his current state of health, but his BMT physician got uncomfortable with the news. His spouse (the caregiver), who had not been in the car at the time of the accident, nevertheless subtly indicated that she was not comfortable with her husband's driving. Despite a fervent protest by the patient the physician instructed him not to drive pending further evaluation. In other cases, the clinicians granted the wishes of the patients or caregivers to allow for their peace of mind. For example, as described in the previous chapter, Mrs. Adams – a patient – felt worried about leaving the hospital when she was cleared to go home by the BMT physician following engraftment. She informed the inpatient team of her fear, who then asked her if she would like to stay a little longer. She was discharged the next day after having told her clinicians that she was more comfortable with the idea of leaving. She was transitioned to outpatient oversight within a day. In another example, Mr. Martin's BMT physician factored in both his travel schedule into town and Mrs. Martin's anxiety about going too long without the treatment in deciding his ECP schedule. And in a third example, Mrs. Isles was asked if she wanted to go home or preferred to be admitted to the hospital at a time when she was going through a difficult period in her treatment. Mrs. Isles recalled asking to be

admitted. In all these cases, the BMT clinicians carefully considered the psychological state, preferences, and self-evaluations of the patients and caregivers.

Importantly, as described earlier, day 100 post-transplant is generally associated with a number of changes. However, when asked about the significance of it, all of the BMT clinicians I talked with – including multiple physicians, extenders, and nurses – independently labeled it as a rather “arbitrary” timemarker. Not one of the BMT clinicians, across all physician teams, identified it as particularly important. On the contrary, they explained that first of all the day itself (i.e. precisely day 100) really means nothing from their perspective. Secondly, although a lot of changes are broadly associated with day 100, in practice they make these changes at different times on a case-by-case basis. They all agreed that both medical and non-medical (or more personalized) factors are considered in making these decisions. Dr. Matthews noted that decision-making is “intensely subjective.” He explained that in terms of clearing a patient to go home, for instance, he takes into consideration factors as varied as a patient and/or caregiver’s attention to detail (as observed through post-transplant interactions), their perceived compliance, their home’s actual physical proximity to the clinic (e.g. a few hours out of town is different from being on the other side of the state), whether the patient has been hospitalized frequently following the transplant, and a sense of how the patient is doing physically overall, among other things. Mrs. Watson – a clinic nurse – noted that a non-local patient might be allowed to go home earlier if the clinicians trust that either the patient or the caregiver is diligent about reporting symptoms to the clinic. She added that in these cases the clinicians ensure that the patient has local contacts (i.e. a hospital, an established relationship with a local physician) in case of an emergency, and the clinic continues to follow the patient regularly through weekly visits. This flexibility is something I observed in clinic visits as well. Similarly, the extenders said that they adjust restrictions based on a patient’s particular situation, confirming that general trust, as well as caregiver and financial considerations are among the common factors that influence leniency.

It is important to note that while these types of considerations often relate to the changes generally associated with the period around day 100, they are not limited to this period. BMT clinicians consider personal factors in their decision-making throughout the transplant process. For instance, at a clinic visit Mrs. Adams' Tacro taper was adjusted taking into account the timing of her next scheduled visit. The taper was scheduled in a way that would make it possible to see whether changes occurred with the next dose reduction and to make appropriate re-adjustments. In another example, Mr. Munro's BMT physician told him that based on the particular circumstances and his preference the clinic could clear him for part-time or full-time work, or provide him with a letter saying he is not ready to return to work yet for medical reasons. In fact, the conversation about returning to work took most of Mr. Munro's clinic visit, where various factors from the nature of the work (e.g. infection risk, need for frequent travel) to his personal preference about working were discussed at length. Finally, after stating the restrictions from his own viewpoint (e.g. absolutely no permission to work in a building where there would be risk of inhaling fumes, definitely no frequent air travel), the BMT physician left the choice up to Mr. Munro who said he would think about it and let the clinicians know. On the other hand, the same BMT physician allowed a different patient to travel more often and be in relatively crowded places (albeit with repeated instructions to wear a mask, not shake hands or hug, and to use hand sanitizer freely) because of an unusual family situation.

Finally, the clinicians note that there is also some practice variation among the BMT physicians in terms of making the kinds of decisions described in this section. For instance, some physicians tend to be more flexible on the driving restriction, letting their patients drive in the earlier months of transplant before the Tacro taper as long as their overall state of health is believed to allow for it. Similarly, some physicians try to be more flexible with travel restrictions. Dr. Matthews said he likes to accommodate patients' wishes for travel within reason, although he has become more wary of it over time. Mrs. Bailey – a clinic nurse – said that they try to accommodate travels, especially because it is not uncommon for patients to take off anyway, but it is one leniency with which they usually have more concern. She said that they then get phone calls from a

hospital in a faraway state asking what to do with the BMT patient who turned up at their hospital with an infection. In general though, the clinicians emphasize that decisions are made on a case-by-case basis, and knowing the patient and caregiver plays a central role.

6.2. Patient Time

While temporalities associated with diseases, treatments, and bodily responses naturally affect patients' and caregivers' experiences of transplant, their view of transplant is rather marked by a series of crises and transitional periods. Diagnosis of a life-threatening disease, the prospect of undergoing an aggressive treatment with many unknowns, a series of re-hospitalizations, and disease relapse constitute multiple crisis situations. To them, the process itself unfolds through a number of transitions: pre-transplant to transplant hospitalization, transplant hospitalization to outpatient follow-up, a period of close clinical oversight to a period of increased freedom (which broadly mark acute and chronic illness periods), and transplant care to survivorship are the more clearly discernable ones. In-between crises and transitions there are often uninterrupted time sequences – periods of stability at the macro level, with ongoing situation management at the micro level. Finally, there are times where misalignments occur between expectations and the reality of illness, what I call *temporal knots*, which call for re-assessment and re-grouping. In this section I examine crises, transitions, and temporal knots to describe their general features.

6.2.1. Crises

When Mr. Roberts first heard his diagnosis his reaction was disbelief: “[Me]? Cancer? Come on! You gotta be kidding me.” He was on a road trip with his wife and daughter when the family doctor called, having reviewed his blood test, to tell him to turn around and go to the emergency room immediately: “This could be leukemia.” Mr. Roberts recalled that at the time he did not know what leukemia was and had to ask his doctor. He was shocked to hear that he had a cancer of the blood. He said treatment started right away and remembered that he “cried like a baby for the whole week.” He blamed himself

and thought about the past with regret. He worried about his daughter being so young and wanting to see her grow up, go to college, and get to be on her own. Coming into transplant and the transplant hospitalization was extremely emotional for him. He recalled being overwhelmed and noted that there was too much going on at the time. He eventually found some peace through his faith with the help of another patient in the hospital, which he described as being essential for him to cope with his situation.

Charmaz (1997) noted that, “In crisis, a radically changed present separates from the past. Like a guillotine, the crisis severs the present from the past and shatters the future. Hence, ill people feel severed and swept away from their pasts into an uncontrollable present and future” (p.33). Indeed, after his initial shock, for a while all Mr. Roberts could think about was his profoundly altered circumstances. His present situation put his past in a different perspective and he mourned a potentially lost future. He said he agonized over how they would break the news to his daughter. As the treatment got underway, he was occupied with coming to terms with what was happening. He had to worry about additional problems, such as making living arrangements in the vicinity of the hospital for the first few months of transplant. He said that the whole process was very emotional.

A high level of urgency characterizes crisis situations. Intervention becomes necessary. Decisions must be made fairly quickly, and activities set in motion to bring about the interventions. Hence, for a patient, a caregiver, and even the clinicians who concentrate on controlling the situation, attention is heightened and the focus shifts squarely to the present. Mr. Moore recalled his son’s first hospitalization when a blood test at the local doctor’s office sent him to the emergency room:

“There was a lot of presence there. Nobody left us alone, okay? So somebody was always there. A resident. A senior emergency room physician. They were clearly paying attention to us. We had apparently some priority in that system, now that I look back on it. But we didn’t really know why they wanted to admit him to the hospital, except that they had to look further and find out what was going on, and that with his blood count the way it was, it was a dangerous situation. And until they addressed that there was no moving forward, you can’t go home. Well, they took us up to the floor, they didn’t really tell us where we were going, the elevator opens and the first thing we see is “oncology.” My mental reaction is: holy shit. As well as my wife’s mental reaction. When they get him in a room, the first nurse or whoever it was we see: Why are we in the *oncology* unit? Nobody said he has *cancer*.” [Emphases original.]

Thinking back to his son's hospitalization, Mr. Moore noted the attention they received from the clinical staff and how the urgency of the situation prevented them from "moving forward" until further investigation could be done. They had not been given a definitive diagnosis (a biopsy was done the next day), and finding themselves on the oncology floor came as a complete shock. In his interview, Mr. Moore remembered a sleepless night, followed by a flurry of activities over the next few days until they were able to settle into a routine with his son's induction chemotherapy. The same urgency and emotional trauma mark all patients' diagnoses and their progress to transplant, unless the situation is not immediately life threatening and transplant is not urgent (e.g. in cases of non-aggressive MDS). Recall the case of Mrs. Isles, described in the previous chapter, who also found herself in the oncologist's office a day after she went for a blood test. Only four days after her visit with the oncologist she was pulled out of work and admitted to the hospital, not realizing straightaway that she would have to stay there for at least a month. With each piece of information she felt "hit" and the situation gradually sank in. She was told within days that she would need a bone marrow transplant. Other patients, particularly ones who had a diagnosis of an acute form of leukemia, also found themselves in the hospital and receiving chemotherapy within hours or days following their diagnosis. None of them could come to terms with their changed circumstances immediately. It was the same for the caregivers (as also recalled by Mr. Moore, quoted above). Mrs. Martin noted the following when her husband was hospitalized for chemotherapy after his disease relapsed and the search for a donor was initiated:

"We will be able to think about [the search for a donor] more after [he] recovers from the chemotherapy. We are still trying to find acceptance in how our lives have changed again."

Even though the transplant process was underway, at the moment the Martins were still trying to come to terms with disease relapse and how their circumstances had changed for the second time. Furthermore, they were focusing on Mr. Martin's current recovery from chemotherapy. They could not quite think about events in the future, although the future in question was not too far away. Mr. Martin completed the chemotherapy regimen to get

his disease into remission. This was followed immediately by the pre-assessments for transplant, the hospitalization, conditioning therapy, and the transplant itself. Five days after her husband's transplant, Mrs. Martin stated:

“We are starting to look ahead a little more. For a while just dealing with everything in the moment was more than enough to absorb. On day 30 [he] will have a bone marrow biopsy to retrieve a sample to see what percentage of the cells are produced from his new immune system and what percentage are from his old immune system. By the biopsy on day 100, a hundred percent of the blood cells should be from his new immune system. Along the way he will discontinue some anti-rejection meds and taper off on his remaining meds. Almost all transplant patients have at least mild symptoms of graft-versus-host disease, or some rejection. [He] will probably start to experience some symptoms in about ten days.”

From Mrs. Martin's statement above, note that only after the transplant was done could the couple look ahead more into the future. Then they focused on the major timemarkers provided to them by the clinicians within the period of transplant they had just entered (i.e. the period of potential acute complications). Mrs. Martin singled out the biopsies on day 30 and day 100, and noted what important information these would provide about the treatment's progress. She had only a general idea of what was expected to happen along the way. Not only did she not look beyond the day 100 timemarkers, she focused on the possibility of acute GVHD emerging in a few days. Hence, it took the crisis situation to settle and the immediate activities associated with it to be completed for the focus to shift, and then mostly to the relatively proximate future and the next stage in the treatment process.

While disease diagnosis and moving into transplant – which are in some cases temporally closely intertwined – constitute major periods of crisis in the transplant trajectory of a patient, they are often not the only ones. Re-hospitalizations, relapses, and the decision to move to hospice are examples of other crisis situations in the BMT world. As noted in the previous chapter, it is very common for BMT patients to have multiple re-hospitalizations in the post-transplant phase. For instance, at the time of his interview more than a year out from transplant, Mr. Scott had been re-hospitalized eight times. Within the first year of his transplant Mr. Martin was re-hospitalized six times. Not all patients get re-hospitalized this many times, but one or more hospitalizations are more the norm. There

are exceptions; a few of the patients I talked with (some in the early months post-transplant and some several years out) were never re-admitted following their transplants. In general though, one or several re-hospitalizations mark times of crisis in the transplant trajectory of patients. These are the times when illness takes a turn for the worse, requiring immediate intervention and close clinical oversight. Unsurprisingly, what patients mostly remember about hospitalizations is just how sick they were. Mrs. Isles, for example, remembered that one time she was re-admitted because her “body just started shutting down again,” but she “came back from that.” Patients and caregivers describe these episodes as scary, disappointing, and discouraging – another “bump in the road.” As with disease diagnosis and transplant, re-hospitalizations also necessitate acceptance and adaptation from patients and caregivers. Mrs. Martin, for instance, noted after her husband’s hospitalization that it had been a “downer” for both of them, but that both of them were “now back on track with the ‘we can do this’ attitude.” She added that, “accepting and facing these challenges is a part of the recovery process.”

Unfortunately, disease relapse is also a fairly common occurrence. Several of the patients I met over the course of this study experienced a relapse. In some cases the relapse was what led to transplant in the first place. The patients described these much like other situations of crisis: emotional times with a distinctive urgency. Mrs. Adams recalled her relapse after more than two years of remission, remembering how miserable it was for her – for months – to follow her counts, knowing that the disease might be coming back:

“I had my regular [follow-up] monthly blood draw. And not even a month, it was quarterly then. Um, and my platelets started to go down then. And they were below, the cutoff was 100, so they were below 100, so then they said we need you to go every single week. So from July until October every single week I went and every week it was like, is it gonna tell me, is it back, are they gonna say do the biopsy? And it just kept going up and down, up and down. Actually, from July to that October was pretty much miserable because every week I had anxiety and then they would call and be like, oh it went up. And then I’m like phew. And then the next week anxiety, oh it went down. You know so they, they pretty much told me it was back. And so then when [the leukemia] came back, that was, that was, it was probably harder to hear when it came back.”

Both in interviews and clinic visits, the level of anxiety that blood counts cause patients and caregivers is unquestionable. Because changes can indicate that the disease is relapsing they are very sensitive to any fluctuation whatsoever, and the clinicians often

have to reassure them that some fluctuation is normal after transplant. For Mrs. Adams, the emotions finally peaked; she says it had been harder for her to hear about the relapse than it had been to hear about her initial diagnosis. Then, from her second remission to her transplant was very fast. The clinic already knew that her sibling was a match and her transplant coordinator was able to schedule the pre-assessments in a very short period of time. In her interview she stated that she was admitted to the hospital on the day she actually got her visit with her BMT physician.

Sadly, in other cases disease relapse occurs post-transplant when the options are relatively limited (especially if the relapse is within the first six months post-transplant). The majority of the patients I have known to whom this happened have passed away. In the few visits that I observed where the patients were informed of relapse, it was always the BMT physician who gave the news. This is generally the norm, given the weight of the matter and the questions that patients and caregivers have at that time regarding their options. The following excerpt from my field notes includes a number of points – which I highlight subsequently – that are common across the visits I observed where the news of relapse was given to patients:

The physician had to give the bad news that the disease was back. When asked about the prognosis he said he doesn't want to be overly negative but also wants to be honest with [the couple]. He explained that the prognosis is not good. The patient took the news without showing much emotion. The caregiver started to cry quietly. There was silence for a few moments. The room was tinged with heaviness, eyes downcast. The patient asked about options. Options include getting chemo, or a clinical trial, or supportive care, or doing nothing with occasional supportive care like getting transfusions if the patient feels very ill. The physician said they can talk about all options and he would leave the decision to the patient. The patient asked, how long [do I have left]? Weeks, months maybe. The physician said he cannot be sure how treatment would affect this; it depends on how the patient responds to treatment. [Conversation about different options.] The patient mostly seemed interested in the clinical trial option. He asked his wife what she thinks about this, and she said it's his decision and she would support him in whatever he chooses to do. (Silence). The patient noted that his daughter was not going to take this well. He also noted that his wife is "going to have issues with [the relapse]." The physician and the extender recommended that they don't tell anyone yet [so that their daughter would not hear it from others], and then to tell their daughter when they're ready for it, in person. (Silence.) The patient asked if he could go home now [he's not local, not yet approaching day 100] and the physician said he could. Have family time, do the things he likes. The caregiver asked what this means in terms of him being able to do things he was asked not to do. What do you want to do? The physician asked. What kinds of things, like food you'd like to eat? The patient said yes, for example he likes to eat at

restaurants. The physician said he could do that but also to be careful and try not to get infections, which would make things worse at the moment.

The following points from the excerpt above are common across the few situations in which I observed news of relapse given to patients. First, the atmosphere was solemn with a lot of emotion in the room. The clinicians respected the weight of the news and allowed intermittent silences. Body language reflected the mood. The conversation eventually centered on potential options. The priority was on decision-making, although the decision was usually not made at the visit. (The physician generally recommended that the patient and caregiver consider the options, and then they would talk again.) Though not included in the excerpt above, the clinicians assured the patient and caregiver that they would continue to help them regardless of which option they chose, adding, “we’re here for you.” Besides discussing treatment options, the physician and the extender actively did emotion work to help the patient and caregiver think through a difficult situation: how to break the news to their child. For the patient, the future became unknown once again; it was not possible to tell for sure how much time there was left. Immediate concerns, such as family reaction and going back home, came to the forefront. In another sense, urgency related to what to do in the time there was left.

All crises – disease diagnosis, moving into transplant, re-hospitalizations, and disease relapse – are marked with certain characteristics: They are times of extreme difficulty where important decisions must be made, and the trajectory of an illness takes a particular turn. All crises are emotionally charged. There is heightened attention to the present situation by all parties involved. There is a sense of urgency. For patients and caregivers in particular, there is just too much going on at the same time; too many unknowns and too many changes. By nature, crises force patients’ and caregivers’ focus to center on the present. The present is too remote from the past. The demands of the present preclude thoughts about the – largely unknown – future, except for the futures that are potentially lost.

6.2.2. Time Blocks and Transitions

The Martins had been looking forward to going home at day 100. Multiple acute complications, including GVHD and various infections, postponed this goal several times over several months, but it remained the goal for them. A few days after his BMT physician diagnosed Mr. Martin's graft-versus-host disease as chronic while they were still living close to the hospital, Mrs. Martin acknowledged that originally their hope had been to return home with her husband "on minimal medication and steadily gaining strength and weight." Now this was not possible. She stated that they still had plans to go home in a few weeks but knew that chronic GVHD would be an issue. She added, "It feels like we are moving into another block of time regarding [his] recovery," describing these "blocks" to be as follows:

"The first block was following his original diagnosis of leukemia; it lasted about five months until the first four rounds of chemotherapy moved him into his first remission. The second block was his remission. The third block was relapse and his two rounds of chemo to bring him into second remission; this block lasted three months. The fourth block was the transplant and recovery in [the city where the BMT clinic is located] which has lasted almost six months. It was, is such a rough time with acute GVHD and two stubborn viruses. No viruses now. This fifth block is, will be the recovery continues after six months; a few more weeks in [the city where the BMT clinic is located], returning home, and living with chronic graft-versus-host disease. So many questions now."

As Mrs. Martin describes in the excerpt above, discernible periods of illness and good health are viewed as distinct time blocks. Each time block has its own distinguishing feature: chemotherapy cycles, absence of disease, more chemotherapy cycles, transplant, acute complications, and moving beyond acute issues. At the same time, "returning home" serves as a specific timemarker – even past its originally expected point, which is around day 100 post-transplant. Initially, for Mrs. Martin going home meant that her husband would be on "minimal medication and steadily gaining strength and weight;" in other words, it meant recovery from illness or getting better. After the diagnosis of chronic GVHD, returning home was still associated with going back to life, albeit – in this case – by adapting to chronic issues. Mrs. Martin's comment "so many questions now" pertains to chronic GVHD, what it means for them, and how to live with it. At the time she made this comment an appointment had been scheduled for Mr. Martin at one of

the chronic GVHD clinics, and Mrs. Martin noted that they would have to wait for the visit “to have more specific information.”

It is common for patients and caregivers to talk about their illness experience using significant markers that separate distinctive periods of time, such as the “time blocks” Mrs. Martin identified. Diagnosis, remission, relapse, transplant, hospital discharge, day 100, and going home are the most common markers by which they subdivide the temporal trajectory of transplant. They refer to specific periods or anchor the time of specific events using phrases such as “prior to the transplant,” “when I came home from the hospital,” “that period of the first 100 days,” “when we were probably home two weeks,” “when he first came out of transplant and first was home,” and so on. Moving along the temporal trajectory is experienced as moving through these time blocks and transitioning between them.

There are several transitions in the transplant process. From the perspective of patients and caregivers, pre-transplant to transplant hospitalization, transplant hospitalization to outpatient follow-up, close clinical oversight to increased freedom from restrictions, and transplant care to survivorship are the clearly discernable ones. All transitions are characterized by changes that require re-orientation on the part of patients and caregivers. Transitions generally involve modifications to established routines, including breaking out of or making adjustments to old ones, and making new ones. There is considerable uncertainty involved in transitions, although the nature of the uncertainty is different from the kind of uncertainty associated with crises. With transitions, patients and caregivers expect certain things to happen, but they do not know how these will work out in practice. For instance, a caregiver expects to assume certain responsibilities once the patient is discharged from the hospital, but what exactly these include and the logistics of it all are not clear at first. There is much learning that takes place. Similarly, patients and caregivers know that – if things go well – there will be certain changes around day 100 that involve more freedom on their part to do things. However, they are not quite certain how these changes will occur in practice. Hence, transitions are information-intensive periods that divide the transplant trajectory into discernable time blocks. For all parties

involved, the time perspective is oriented towards the future and the changes associated with the future.

In the rest of this section I briefly describe two transitions – transplant hospitalization to outpatient follow-up, and a shift from close clinical oversight to a period of increased freedom – in order to highlight some of the broad characteristics of transitions.

Example Transition 1: Transplant Hospitalization to Outpatient Follow-up

Leaving the hospital following transplant involves major changes for both patients and caregivers, and it is a particularly challenging transition for the latter. The discharge is the time at which many of the responsibilities outlined in the formal caregiver agreement come into effect, and should – technically – remain in effect until at least day 100. As described in the previous chapter, these responsibilities are extensive. The caregivers I interviewed or had informal conversations with all singled out the time after hospital discharge as the most difficult for them. For instance, Mrs. Collins noted that once her husband left the hospital there were multiple changes in her life. She had to develop new routines at home – giving medications and IVs, changing the dressing on Mr. Collins’ catheter, giving him a daily bath – in addition to the things she was already used to doing. Besides these new routines, she had to take over the errands that Mr. Collins would normally do. She described the transition from the hospital as getting “acclimated back to being home:”

“Probably the hardest for me was just getting [him] acclimated back to being home, cause he’d been in the hospital for a month. And then I was like really nervous because I didn’t want to do anything wrong. I was double-checking and triple-checking the meds to make sure I was giving him the right amounts, when, and make sure I did the IV right and there was no infection, cause we didn’t want an infection in there. It was like (inhales deeply). That was probably more stressful of anything. And making sure he was eating and drinking enough... Hectic. It’s much better now [just beyond day 100] than what it was when he first went home, cause of the IV and the dressing changes, and we had to have his daily bath. And I always had to do them after, cause I worked. So I’d come from work, get the bath done, get the IV started, cause it ran for four hours. Made dinner. Made sure we ate and cleaned up and that kind of stuff... But it’s really difficult and I think you don’t realize how difficult it is till, I mean, even when he worked he worked in the afternoon. So he was home all day. So if I had errands, if I had to go to the post office, the bank, the pharmacy, the drugstore to pick up some stuff or a few things from

the market, I just left him a list [of things to do] and he did it. Well now he doesn't do it because he doesn't drive. So I have to do all that in addition to working. And that's probably the hardest thing."

All caregivers reported similar experiences as Mrs. Collins, describing an overwhelming situation following the patients' hospital discharge. Even Mrs. Martin, who on the day of her husband's discharge stated that she felt comfortable with the expectations for his caregiving, noted only two days later, "I really hope that it feels like we are getting into a routine in a few days. I now appreciate those hospital floor nurses more than ever." Part of the difficulty – which led to more appreciation for the nurses – stemmed from the fact that caregivers have to acquire knowledge and skills that are in most cases entirely foreign to them coming into transplant. Mrs. Scott, for example, recalled that she "had to learn *so* much more than [she] *ever* wanted to know,"²⁴ noting that even though she was never into anything medical she had to learn how to do IVs, give shots, take care of picc lines²⁵, ensure there were no germs, and knew the kinds of food she should or should not give her husband. The knowledge and skills were not only new, they had to be used in a context in which there was incessant worry about making a mistake. Mrs. Isles remembered how the first time her husband was learning to give the magnesium infusion he did not connect the line to her catheter the whole way. She suddenly felt something wet on her stomach and looked down to see blood all over her shirt and the couch she was sitting on. After the incident her husband decided that there was "no way" he would try giving the IV again. Mrs. Isles noted that he eventually got really good at it, but it took a while for her to talk him back into it. Mrs. Davis – caregiver to her husband – also worried about making a mistake. She remembered having a hard time in the beginning, but much like other caregivers noted that after a while "you got to know your routine."

Many of the caregivers indicated that what they did for their patients was complex work. It took time for them to acquire the necessary knowledge and skills. Once they did, they generally preferred not to have anyone else take the responsibilities because there was simply too much to know to fulfill these responsibilities adequately. For instance, in his interview, Mr. Lawrence – caregiver to his wife – contemplated the idea of having

²⁴ Emphasis original.

²⁵ A picc line is a type of intravenous catheter.

support from others in the caregiving process (as he had done everything himself), deciding that he was not sure if it would be “worth it.” He reasoned that the amount of information you needed to know to be an effective caregiver was simply too much, and that it would require him to teach others in turn. “It’s tough learning,” he noted.

Whereas the transition from transplant hospitalization is particularly challenging for the caregivers, it is nevertheless a significant transition for the patients as well. They also adapt to new routines, both at home and at the BMT clinic. At-home routines include medication schedules, IV infusions, as well as sleeping, bathing, eating, and even (water) drinking routines. On the other hand, even though the patients and caregivers have some familiarity with the BMT clinic from the pre-transplant phase, the clinic environment is also new to them in many ways in the post-transplant phase. Outpatient clinic life – as described in the previous chapter – is very different with its own structure and rhythms. Hence, for the patients and caregivers acclimatization to outpatient care is not limited to changes in home life; it includes learning and adapting to the organizational routines of the clinic. There is much know-how involved in navigating the system. As they transition into outpatient care, the patients and caregivers must learn how outpatient clinician teams operate, how internal processes work, and how to communicate with the clinic, among other things. By the time they reach the next transition in the transplant process, they often have considerable expertise in working within the system.

Example Transition 2: Loosening of Clinical Oversight

“It’s a lot of running down over here. Like today, I mean this whole day is wasted because, you know, by the time we get done with all this [points at the IV], I get home, you know it’s a whole day out of my life. And there are a lot of them. And so, you know, you’re not happy with the inconvenience. But in order to recover, in order to get better, you have to do what you have to do.”

Like Mr. Davis, quoted above, BMT patients and caregivers often note that their time is dictated by clinic schedules and the routines of patient care. This is particularly the case in the first few months post-transplant. Blood draws, tests and procedures, frequent clinic visits, IV infusions (both at home and at the clinic), daily shots, ECP and other treatments, and so on, drive their lives. This is so much so that a few of them have

indicated that time essentially does not belong to them; they are told where to be, what to do and when to do these. Mrs. Martin, for instance, often commented on how wonderful it is to be able to relax on one's "own schedule," such as on weekends when illness routines are generally less demanding. Mrs. Scott noted that it was impossible to go anywhere or do anything because doctor's visits and her husband's illness never left any time. Given the *immersion* in illness (Charmaz, 1997) in the first few months, one of the key goals for patients and caregivers becomes reaching a point where clinical oversight would be relaxed to an extent, illness routines would lessen, and major restrictions would be lifted. Essentially, in a way the goal is to gain ownership of time – and life – once again. Based on the way that the transplant process is initially outlined for them, most patients and caregivers associate day 100 with many of the anticipated changes. They view the timemarker as a major milestone that leads into a new time block in the transplant process.

While patients and caregivers view day 100 as a milestone, which they generally associate with getting better, observations of clinic visits show that there is considerable uncertainty regarding what the transition exactly involves. The patients and caregivers are generally aware that a bone marrow biopsy will be done, and understand that it is important to see if the disease is still in remission. Those who are not local residents are usually aware that there is a chance they might go home. There is the anticipation that the frequency of clinic visits will decrease. There is also awareness that additional changes might take place in terms of restrictions being lifted and precautions being relaxed; however, patients and caregivers are often not sure what these involve. As is generally the case with patients, once Mr. Reed learned that his day 100 biopsy showed no evidence of disease, the first thing he asked was what he was allowed to do now. He was very enthusiastic about going back to doing "anything and everything:"

The couple [i.e. the patient and caregiver] said they were not surprised by the biopsy results, but they were very happy. Mr. Reed said he would like to know what he could do now. His physician asked him what he would like to do. "Anything and everything," replied Mr. Reed, so enthusiastic that he drew laughter from everyone in the room. He said that he would like to have cheese, so what kinds of cheese could he have? This led to an extended conversation about various kinds of cheeses. The physician finally stated that he should only have pasteurized cheeses. Mr. Reed said he would also like to mow the

lawn and joked about doing this chore. As the laughter died down the physician insisted quite seriously that he should not expose himself to the dust and dirt. Finally, Mr. Reed asked if his port [i.e. catheter] would come out. The physician confirmed that they would schedule its removal.

Note that, as is the norm among the clinicians in general, Mr. Reed's physician answered his question regarding what he could do by asking what he would like to do, instead of providing the couple with a generic list of items. All of the topics Mr. Reed brought up related to some sort of restriction; his wishes had to do with wanting to be freer from changes imposed by illness. This is common in clinic visits where day 100 is discussed. For instance, Mrs. Adams asked if she would have to continue a particular medication for her eyes until day 100, because she was instructed not to use contact lenses while on the medication and she did not prefer wearing glasses. Mrs. Collins – a caregiver – wanted to understand why her husband wasn't allowed to drive their car. Mr. Baker wanted to know if he could use his hot tub after his catheter is removed. Essentially, in his visit Mr. Davis explicitly associated changes with having more freedom: "So this is day 100. What happens next? Am I more free to do things?"

It is important to note that while many patients and caregivers associate anticipated changes with day 100, it is also common for various changes to happen at different times in a patient's transplant trajectory. The main timemarker that often gets substituted in place of day 100 is "going home," depending on when the patient and caregiver get to move back home. As discussed under "Clinician Time," decisions such as these generally depend on the discretion of the clinicians, although patients and caregivers actively negotiate – or "break rules" – as well. Essentially, what makes day 100 an important transition (from the viewpoint of patients and caregivers) is the meaning they assign to it: getting better and having more freedom. Hence, to them, this timemarker divides being sick, at risk for relapse, and having no freedom, from getting better and gradually gaining back freedom. Those are some of the features of the "time blocks" that the transition separates. As I will discuss in a subsequent section, this viewpoint differs significantly from that of the clinicians.

6.2.3. Temporal Knots

“Do what the doctor says in the first two years before you’re trying to go back to being the type of person you were. [Interviewer: That’s what you were doing? Trying to go back to who you were?] Yes. It’s a natural, natural thing... You realize you can’t have it... You’re so new into [the transplant] that you just can’t shut yourself off. And so it’s trying, especially a guy like me, so you keep on trying to get back to the guy you were and it’s not gonna happen. And it takes a while to get a hold of that.”

Many patients, like Mr. Roberts quoted above, have at first a rather constrained idea of the transplant process – and associated illness – that resembles Charmaz’s (1997) description of illness as an *interruption* to normal life. This is closely related to what was discussed in the previous section with regards to freedom and control over one’s own time and life. Of course patients are not naïve in the sense that they only consider the possibility of a full recovery. For one, they are keenly aware of the risk of death, possibly from disease relapse, but also potentially from complications from the transplant itself. They do not know how far the future stretches. In new patient visits, potential complications that might significantly affect quality of life – most notably GVHD – are also discussed. However, what recovery or dying would mean is much clearer in comparison to living with unknown or unfamiliar chronic complications. Hence, particularly at the beginning, the temporal perspective of patients and caregivers more readily matches that of going through an acute illness: one may die from it, otherwise the process is to be traversed and the patient should emerge from the other end with a new immune system. What more than that cannot be imagined. So, the focus largely remains on returning to normal life, even as patients and caregivers fear complications, while also accounting for the fact that death from the process is possible. Therefore, both funeral arrangements and questions pertaining to a normal future, such as returning to work, are typical.

In most cases, the patients and caregivers base their conceptions of the likely illness trajectory on their BMT clinicians’ initial descriptions of the bird’s eye view of the transplant process, and the information in the printed material given to them (if they read it). For example, questions directed at clinicians at visits prior to transplant commonly pertain to the overall transplant schedule: what conditioning regimen the patient will get

and when, what day the transplant will be on, the expected duration of hospitalization, and general timemarkers in the post transplant period (e.g. for out of town patients, when to return home). Patients and caregivers also receive a rough timeline of significant events, such as when acute or chronic GVHD may occur, when to expect to drive again, when to expect to go back to work again, when the patient may be off all immunosuppression, and so on. All this information serves to formulate an *expected trajectory* of illness.

An important point to note here is that what the patients and caregivers conceptualize as the expected trajectory generally represents a much simplified version of the “best-case scenario” for BMT clinicians, who often use this phrase in transplant consultations and later at clinic visits. Still – as discussed further below – for the patients and caregivers the expected trajectory tends to form the basis of a “normal” transplant course, which they then use to assess deviations from the normal. In fact, patients sometimes even dismiss the clinicians’ conceptualization of the best-case scenario, such as when they believe that they will return to work much sooner than a year. The idea of an expected trajectory, coupled with the patients’ wish to regain their normal (pre-illness) life, sometimes leads to significant misalignments between expectations and the reality of illness; what I call *temporal knots*. Next I provide two examples, one from the earlier months post-transplant and the other from later in the transplant process.

One of the most common complaints of BMT patients is the extreme fatigue they feel in the months following transplant. As described in the previous chapter, patients report sleeping all the time, not being able to do anything much at all, and never having experienced anything like it. Mrs. Allen recalled that she couldn’t even pick up the sheets on her bed and she could barely open the refrigerator door. Mr. Davis described it as feeling like “they sucked everything out of you.” It is also quite common for caregivers to ask at clinic visits and over phone calls why their patients are sleeping twenty hours a day. Hence, this prolonged fatigue tends to perplex both patients and caregivers considerably. At two successive clinic visits only a few days apart, early in the second month of his transplant, Mr. Harris expressed disappointment and depressive feelings

about the fact that he was not feeling better at this point in the process. The extreme fatigue had cost him his independence in many ways. The following are excerpts from my field notes on his visits:

When the extender asked how he's doing, the patient [lying down on the hospital bed in an infusion room] responded that he has been feeling okay, but that it is a bit disappointing to him that he is not feeling better at this time. He said he thought he would feel better at this point [in the transplant process]. "I've always been a very independent person," he said, adding, "Not to say [my caregiver] is not helping, she is. But getting help putting your socks on. And not being able to do things outside. It's been depressing, you know." The extender had informed me before we left the teamroom that the patient's been keen on doing things outside a little too soon. She now repeated this to the patient, adding "I know you wanted to get right back into things." The patient said he doesn't enjoy having to stay inside and not being able to do much, even noting that he used to run in this weather [which is in fact very cold these days]. "It never stopped me," he said.

[At a clinic visit the following week]: When asked how he is doing by the extender, the patient reported that, "there is no enthusiasm." He talked a fair bit about how "down" he is feeling. He repeated what he said last week; that it's hard for him to ask for help for things [putting on clothes, cleaning the yard]. The patient asked why this is happening to him, "is it the transplant, is it the chemo?" The extender reassured the patient that this is very normal for someone who is at this point in the process.

As seen from the excerpt above, Mr. Harris became reliant on his caregiver and others for daily living functions and compared his current infirmity with his previously healthy self, who would have gone running in cold weather. Going from that to not being able to put his clothes on by himself was a major change for him. His expectation had been that he would be feeling better by this time – two months after the transplant – than he actually did. On the other hand, the extender noted, even before the first visit, that Mr. Harris had been keen on doing things "a little too soon" and trying to "get right back into things." Clearly, the extender's view of where Mr. Harris is in the temporal trajectory of transplant was different than the view that Mr. Harris held himself. In the second visit, Mr. Harris tried to understand why this was happening to him – is it the chemo, is it the transplant, or perhaps it's something else? The misalignment between his expectations and the reality of illness prompted psychosocial responses and clinician work to reassure him and to readjust – or realign – his expectations regarding the illness trajectory. This particular misalignment is quite common. Mrs. Kelly – an extender – who noted that she spends half her time in clinic visits trying to explain to patients that it is common to feel like this this far out from transplant, also said that patients tend to compare their progress

in recovery to how it was after they got all the other chemotherapies prior to the conditioning therapy. That is the only comparison the patients are able to make in terms of trajectories of recovery based on their own experiences.

Similar issues occur at other times in the transplant process. For instance, as described in the previous chapter, the clinicians hope to get a patient off all immunosuppression if possible. The earliest this could happen is by six-months post-transplant, but that doesn't happen very often. There is a better chance to be off immunosuppression by the one-year anniversary of transplant, although there are no guarantees because of the possibility of chronic GVHD; many patients remain on some amount of immunosuppression longer or even permanently. In the following excerpt, Mrs. Lawrence recounts how she actually sunk into depression when she could not reach her own expectation of being off immunosuppression by her second-year anniversary:

“So I didn't make the one-year to get off immunosuppressants. So then I had this in my mind, “well, by two-years.” So if I can, you know, if the leukemia doesn't come back and the GVHD doesn't get worse and I can get off some of these medications two years past transplant, then I would be ready to go back to work the following fall. And it was just like something I had like built up in my mind, that I was going to be not taking all these pills that remind me everyday that I'm still a leukemia patient and a transplant patient. And so it was like this big, um, I didn't realize that I had created this kind of, you know, end of the line, you know, be free of leukemia, that I'd attached all this meaning to this two-year anniversary which I hoped to be off my immunosuppressants. Well, it was at this time when I recognized that the joint issues were GVHD. So I wasn't going to be off the immunosuppressants. And that was a very very difficult time for me. One (pauses), I would say probably one of the most difficult times, you know, past you know the first six months after transplant. And it was the recognition that this will be a long-term thing. Um, you know, that I can't really, like, put the leukemia entirely behind me. Um, you know I worried that it might interfere with my ability to go back to work. You know, and it was exactly at that time that I asked to be put on an antidepressant. And I went to therapy. So it was significant. It was a significant issue for me.”

In Mrs. Lawrence's experience, with the recognition that illness is not an “interruption” to life – however extended that may be – but a long-term challenge, came discouragement and even more significant psychosocial responses. Her expected trajectory had to be updated or realigned. Mrs. Lawrence noted later in the interview that the BMT clinicians had in fact not set the second year anniversary as a timemarker; they had left the trajectory to unfold while Mrs. Lawrence herself hung on to the idea of recovery:

“So in year-two we really got to start weaning down and I had gotten so close, you know, 12 pills, 10 pills, you know, 8 pills, 6 pills, 4 pills. You know then I was on like 2 pills a day (laughs). And down to 1 pill. And I was going to go to my two-year anniversary appointment, and I thought okay, this is my two-year anniversary appointment and I’m coming here and no pills. And if I’m not on the immunosuppressants, I didn’t think that I needed to be on the antivirals and the antibiotics and, you know. So, and when that didn’t happen it was, um (pauses). And I think this was totally self-imposed, I want to say that. You know, there was no guarantee from anyone that I would be off these immunosuppressants. But we were clearly moving in the direction. You know, as we were tapering over a very long period of many months. Um, and when that didn’t happen it was, it was a psychological trauma for me.”

It is important to note that the view of illness as temporary – which many patients hope for – is despite explicit warnings by the BMT clinicians at this site, in the pre-transplant period and beyond, regarding the fact that patients will likely never be the same as how they were before getting ill and having a transplant. This is signified by the idea of reaching a “new normal” after transplant, which is common parlance in the BMT world. Foreshadowing it early on is a part of informed consent, and a way to manage patient and caregiver expectations. Yet, many patients at this site still focused on the idea of returning to the normal they knew, and got disappointed when they found that this goal was out of reach.

In BMT in general, there is a spectrum of what could constitute a “new normal.” In some cases the patients are able to resume life without major chronic issues, but persistent fatigue, loss of stamina, and poor short-term memory are among long-term effects for the majority. In other cases one or more chronic issues arise that further affect quality of life. At this site, in the worst-case scenario, some patients questioned whether the transplant had been “worth it.” The quality of life was so impaired that the value obtained from being free of the original disease was deemed negligible. In one case I observed, the caregiver told the patient’s BMT clinicians (while the patient was absent from the room) that the patient felt the whole ordeal “was not worth it.” The patient’s demeanor during the visit also showed a dejected veneer. In conversations with BMT clinicians, they have noted that they too are not immune to such remarks and feelings, which they acknowledged does happen sometimes; it is difficult and sad for them to hear these. In a happy turn of events, several months after this caregiver notified the BMT clinicians of

the patient's psychosocial state, many of the patient's GVHD issues resolved and other issues became more manageable. The patient came for a clinic visit unaccompanied by the caregiver, at which time he told the clinicians in an upbeat manner that he was, "Really doing great. Back to working part-time. Almost back to normal!"

Temporal knots occur when there is misalignment between a patient or caregiver's expected trajectory and the actual trajectory of illness. The examples provided above are common among patients, but knots can occur at any point in the transplant process. This is in part why it is dangerous to have patients compare themselves to other patients, especially in BMT where "no two transplants are the same." BMT clinicians try to prevent this problem by actively warning their patients not to compare themselves to others. On the other hand, some patients also try to manage their own expectations by occasionally asking their clinicians if they're doing how they are supposed to be doing at the stage of the process they are at. Otherwise, it's important to gauge a patient's expectations in order to readjust these if necessary.

6.3. Temporal Misalignments

So far my goal has been to illustrate the different ways in which BMT clinicians, patients, and caregivers experience and envision the trajectory of transplant. In this section I use three cases to illustrate how temporal misalignments raise particular challenges and implications for information work.

6.3.1. Case 1: Initial Crisis and Information Overload

Mr. Moore was actively involved in his son's treatment throughout his illness and the transplant process. Highly educated, he diligently researched everything from healthcare facilities to the particulars of research protocols and details of treatment. He learned, observed, discussed, and at times pushed back to make more informed decisions. However, when asked how he dealt with information when his son first entered the

hospital for leukemia, Mr. Moore noted that his goal had been to attend to immediate needs:

“I think it was: go home, bring him what he needs. He needs his computer. He needs some books. He needs cell phone. Um, and, just try to figure out how we’re going to *manage* with this. The, I mean on Friday, that next day I had to cancel a whole bunch of business trips that I was planning to make just the following week. So I was on the phone with my business colleagues telling what’s going on, and getting out of the travel that I was expecting to do within the next month-long period. Taking care of that. Um, [my wife] still had a fulltime job at that point. I knew I was going to have to take some time off, so the wheels were turning about what we’d have to do to deal with this. Cause, it was clear it was going to be a long-term process. The drugs, yeah they hand us a sheet that would talk about it, what the side effects are, and that’s all I could really cope with at that point in time.” [Emphasis original.]

As is evident from Mr. Moore’s description above, once his son’s diagnosis was made his priority became preparing for what he correctly recognized would be a long-term process. He had to make a whole lot of arrangements at work, and to support his son based on the family’s particular circumstances. As for information regarding treatment, there was only so much he could cope with at that point in time, which paled – significantly – in comparison to what he was able to do later.

As described earlier in this chapter, crises are times of extreme difficulty marked by a sense of urgency and emotional turmoil. They are times in which the trajectory of an illness takes a particular turn. For patients and caregivers there is too much going on at the same time, too many unknowns, and too many changes. Most importantly, a crisis forces the attention to be centered on the present. That time shrinks – for all practical purposes – to the present, and focus shifts to the moment, has profound influences on one’s experiences, including their responses to or interactions with information. For the patients and caregivers in this study, it was challenging to absorb and process information provided to them in the midst of a crisis. It was even more difficult to do so when the information concerned events in the relatively distant future.

That it can be difficult to concentrate and to absorb information during a crisis – especially information pertaining to the future – has important implications for transplant education, and how patients and caregivers learn to navigate the process and effectively

participate in the management of illness. In BMT, the sheer amount of information that the patients and caregivers must receive, process, and act on is enormous. *Information overload* is consistently singled out in conversations and interviews as a major challenge in the process. Although there are many information-intensive periods in BMT, the patients and caregivers – and in fact clinicians – in this study identified the period prior to transplant, when preparations for transplant are underway, as particularly problematic. At that time the information overload is multidimensional, as I describe below. At that time the clinicians are trying to optimize the timing of transplant, and set in motion a series of activities to bring the patient to transplant as soon as possible. At that time the patients and caregivers are in crisis. Hence, at that time the clinicians’ present activities – such as providing information about potential complications and necessary precautions during transplant – are oriented towards the future, but the patients and caregivers are stuck in the present and barely able to cope. Thus, the crisis involves a misalignment, and necessitates much information work further into the process for the patients and caregivers to actually learn what they must to manage illness effectively. As I discuss shortly, at the time of the crisis very little, if any, information is retained unless it is of immediate practical value.

It is important to unpack what “information overload” involves. First, the information covered in the pre-transplant period pertains to a wide range of topics and is presented in person or provided through printed material in considerable detail. From the donor process to catheter placement, conditioning regimen to infusion of stem cells, patient responsibilities (e.g. nutrition, hygiene, physical activity) to caregiver responsibilities, source of stem cells to chemotherapy side effects, complications (e.g. fever, infection, bleeding, organ toxicity, and so on) to acute and chronic GVHD, side effects from immunosuppressants and steroids to hospital discharge planning, housing arrangements to post-transplant follow-up, and post-transplant restrictions to recovery challenges (among other things) are reviewed by the clinicians and in the transplant handbook as part of informed consent and patient education. The amount and variety of information, as well as receiving it with a background in accounting (for example) versus a background in a medical field – as Mr. Lawrence, a caregiver in this study, noted – can

make for a challenging situation. Mrs. Lewis (a patient) and Mr. Lewis (a caregiver) also commented on how difficult it was to process and comprehend so much information:

Mr. Lewis: “[The printed material] was like two hundred pages. There’s no way you could digest that much information, you know. If you could somehow space that out in bite sized pieces that would be a big help, instead of sending people home with five pounds of paper that they’ll never read.”

Mrs. Lewis: “And then I was on these studies too and you had all those papers to read for the study. It was a *lot* of stuff. It was a lot to comprehend.” [Emphasis original.]

In the excerpt above, Mr. Lewis – the caregiver – states that it was particularly difficult to digest the information in one sitting, that it would be beneficial to receive it in smaller chunks over time. Although in this instance the conversation centered on printed material, face-to-face information exchange with opportunities for asking questions to clinicians also necessarily occurs in a short period of time relative to the complexity and amount of material covered. Most of the information is reviewed in bulk in hour-long separate meetings with a BMT physician, transplant coordinator, and social worker. Although the clinicians make every effort to answer all questions directed at them during these meetings, the processing time for patients and caregivers is limited – which is the second facet of the information overload. Transplant coordinators have stated that they frequently receive phone calls from patients and caregivers with questions that pertain to the information covered with them in meetings. As it was the case with Mr. Moore, the caregiver who focused on preparing for his son’s transplant by making family and work-related arrangements first, the questions patients and caregivers tend to ask transplant coordinators often concern practical matters (such as finding an apartment in the city) rather than any information regarding the later periods of transplant (e.g. infection precautions or GVHD).

The complexity of the medical domain adds a third layer of difficulty. A mental model of how transplant works, potential complications, the interrelationships between various complications and interventions, the purpose of the many medications, reasons behind restrictions, and so on, are not immediately accessible to the layperson. As noted in the previous chapter, there is usually no familiarity with these prior to transplant, and

absolutely no experience before issues actually emerge during the process. As Mrs. Martin – a caregiver – noted, “Hearing that there will be bumps in the road and living through bumps in the road are two entirely different things.” Moreover, it is not possible to know in advance what kinds of issues – and consequently information needs – will eventually arise for a certain patient. Therefore, building enough understanding and knowledge on a case-specific basis takes time and experience through the concerted efforts of the patient, caregiver, and their BMT clinicians. This happens throughout the transplant trajectory of the patient, in context, as the trajectory unfolds.

Another facet of information overload in this period of crisis – in fact, in any period of crisis – is the considerable emotional impact of the information received. Potential death from complications, disheartening survival statistics, preparation of a living will, possibility of an impaired quality of life, having to relocate from home, separation from children, and other information, are difficult to digest. As noted earlier, some patients make their funeral arrangements and put their affairs in order prior to transplant, and try to cope both with their own fear and those of family members, particularly their children. Hence, in the midst of a crisis it can be exceptionally challenging to envision issues – and digest corresponding information – that may arise much later in the transplant process when the focus is still on preparing for transplant and trying to accept radically changed circumstances. For instance, Ms. Lauren – a patient – had her information session with her BMT physician in the hospital when her disease relapsed and she had to move to transplant quickly. She was clearly overwhelmed by all the information she received, and chose to selectively focus on what was immediately relevant to her situation:

“I remember [the BMT physician] talked about side effects, of graft-versus-host disease, but it was overwhelming. It’s like, I don’t know. You know what, I’ll, I mean, it was just *so* overwhelming when I’m sitting (laughs nervously) there in the hospital bed and he says, you know, here’s what happens next. And I have to move to [names city where the BMT clinic is located] for three months. I’m like, and I needed somebody with me 24/7. I’m like, what? How am I going to do *this*? You know? Where am I going to live? What do you mean I have to live within, have to live within thirty minutes of the hospital or something like that? I live in [names other city], almost two hours away. I’m single with no kids. I mean, you know, I’m like, what? Who’s? You know. Yeah, you just do it. So it was very, everything was *very* overwhelming. So then when he talked about graft-versus-host disease I’m like, you know I don’t know what that is (laughs a little). You know? I’ll cross that bridge when I get to it.” [Emphases original.]

As she explained further into the interview, Ms. Lauren was also overwhelmed by the fact that she would lose her job, her main income. In the midst of this crisis she could not bring herself to learn much about graft-versus-host disease, noting that she would “cross that bridge” when she got to it – when the information became more relevant from her perspective. On the other hand, her physician had to provide the information for purposes of informed consent. The situation for the clinician is also delicate, because at this point in a transplant BMT clinicians are just beginning to establish a working relationship with their patients and the caregivers; it is more difficult for them to gauge responses to information delivery and tailor to particular information preferences. For instance, Ms. Lauren also recalled in her interview how she did not want to hear any survival statistics, and deliberately avoided information in general in order not to run into that kind of information. Many other patients noted that the information they received was “a lot of negative,” to quote Mr. Roberts, and chose to avoid it. On the other hand, other patients and caregivers wanted to know as much as possible. Mrs. Adams, for example, said she treated the transplant handbook as her “transplant bible” and followed the information in it religiously. Since the clinicians tend to have their “own spin” on the material provided in the transplant handbook, Mrs. Adams would sometimes find that it is not possible – or necessary – to follow the handbook so closely. As a caregiver, Mr. Moore researched everything, following every detail and fully immersing himself into the treatment process. He is an exception in many respects, as he – after the initial shock – was future-oriented in that he tried to anticipate and think through questions and problems way in advance. There is then a range between the two extremes where patients choose exactly what to know. For example, the patients and caregivers in this study chose whether or not to review consent forms for clinical trials in detail. It takes time for the clinicians to find out the best ways in which to provide the necessary information, and for trust to develop between all parties. This is part of “getting to know” the patient and caregiver, as described earlier. This also happens over time, as the patient, caregiver, and clinicians work together during the course of the transplant.

Another level of difficulty arises from a patient's level of engagement, besides willingness to learn. A patient may be willing to learn but unable to engage. Having "chemo brain," memory problems, fatigue or physical pain – all common among BMT patients – can considerably affect a patient's level of engagement or ability to process the information provided. In support group meetings, patients have said that they suffered from "chemo brain" prior to and in the early stages of transplant. They had chemotherapy, in some cases several cycles, before they got to transplant. Mrs. Gordon noted at a support group meeting that her caregiver served as her "eyes and ears" in the process, and that she would otherwise miss important information. Mr. Bennett, a caregiver, said that he paid particular attention to information because his wife had endured too much chemotherapy, and too much treatment overall, to be able to concentrate on and remember information.

In effect, in this period of crisis, patient and caregiver time perspectives are focused on the present. They are more concerned with the immediate arrangements they must worry about in order to prepare for transplant: finding a caregiver, relocating, organizing finances, making funeral arrangements, and so on. The urgency with which the current situation must be addressed, along with the emotional turmoil caused by it, distance those who are directly experiencing it from the future. Under such circumstances it is difficult to understand and process information, and patients and caregivers try to focus on what is more immediately relevant. This has implications for transplant education and how patients and caregivers learn to navigate the process and effectively participate in the management of illness, because the transplant process necessarily begins with a crisis situation. Transplant education is given at this time both for purposes of informed consent and preparation for transplant. Essentially, the clinicians' time perspective is also focused on the present, but the activity required of them in the present involves covering information pertaining to the future. It is not surprising then, that the inpatient team finds that patients and caregivers do not remember much from their pre-transplant information sessions. They filter the information to focus on certain aspects and leave much of the rest to later in the process when the context becomes more amenable to learning. This has implications for information work throughout the transplant process; requiring

information to be repeated, re-explained, reinforced, and provided with optimal timing for learning.

6.3.2. Case 2: Day 100

“Disease relapse, [the risk is] way high first one hundred days, for sure. Acute GVHD, way high first one hundred days. Perhaps from that perspective it’s possible to view it as a milestone. It’s a milestone, but it’s not a major milestone. [The] patient is not out of the woods yet. But it may seem like more major to patients because they get to go home.”

In the quote above, Dr. Matthews essentially pinpoints a major misalignment between clinician and patient perspectives associated with the significance of day 100, and what it entails for the trajectory of illness. As described earlier, BMT clinicians envision a trajectory in large part based on their knowledge of the temporalities of diseases and treatments, and the responses of a patient’s body to illness and interventions. They also make personalized assessments to judge the patient’s risk for complications (such as attention to detail, compliance, or previous hospitalizations), which helps to determine the necessary clinical oversight. Through a combination of this knowledge, the patient’s history of complications and current state of health, they are able to conceptualize the trajectory of transplant, including a potential future trajectory. From this perspective, day 100 means that certain risks are lower, but it does not necessarily mean that the trajectory will continue on a favorable course or that a patient has recovered. As Mrs. Bailey – a clinic nurse – noted, “it’s not like [the patients] suddenly get better on day 100.” As all of the clinicians independently and unanimously stated, to them day 100 is rather “arbitrary.”

In stark contrast, the patients and caregivers put a lot of weight on day 100, even on the actual day itself. Mrs. Watson – a clinic nurse – observed that patients and caregivers tend to view it as a “magic” timemarker. Clinic observations support her point. For instance, when Mr. White was eighty-two days out of transplant he noted at his clinic visit, “Eighteen days and counting.” His wife asked whether they should schedule a clinic visit on his day 100, because the actual day did not fall on one of the physician’s regular clinic days. I have actually heard the same question get asked by other patients at their

clinic visits. Mr. Bryant joked with his clinicians that he would like a cake from them on his day 100. Mrs. Kelly – an extender – said that patients put so much weight on the day that she sometimes gets questions such as, “today is day ninety-two, do I get to go home in eight days?” As described earlier, the patients and caregivers associate day 100 with the lifting of restrictions and relaxation of certain precautions. A negative (i.e. disease-free) biopsy offers further reassurance and adds even more weight to the significance of the timemarker.

As Mrs. Kelly – an extender – noted, from a clinician’s perspective day 100 means re-staging of disease and reassessment of where the patient is in her or his recovery. She added that it is also a time in the process where she actually gets a little nervous, because it is not possible to know what is coming next. Although a negative (i.e. disease-free) biopsy is very good news, it does not mean that the disease will not come back after that point; relapse is still a significant concern. Relapses, especially in the first six months, do not tend to have good prognosis. Additionally, since the Tacro taper will be starting, there is the concern about chronic GVHD. Although some GVHD is good for its beneficial effect against disease, it can also severely impair quality of life. Chronic GVHD is stealthy, “it can kind of sneak up on you,” as BMT physicians sometimes describe it. However, since the frequency of clinic visits generally decreases for a patient around day 100, it falls to the patient and caregiver to be extra diligent about keeping a close eye on any emerging symptoms. This makes the clinicians nervous when the patients and caregivers instead associate the timemarker with getting better. The following excerpt from my field notes on Mr. Collins’ day 100 visit provides a good example of why BMT clinicians are so concerned about the transition:

The patient, having received the biopsy results, shook his physician’s hand and told him, “You’re the man! You are.” The physician acknowledged the good biopsy results, but did not comment on it any further. He noted that they would now begin the Tacro taper and described how that would happen. The patient, looking somewhat confused, asked whether the physician has some trepidation. The physician said while the biopsy results are good, he wants to make sure that the patient knows they are not quite done yet, the patient still needs to work at it. “Things can still happen,” he noted. “Well, the disease can still come back. And now with the Tacro taper things can happen, more chronic kind of GVHD.” He explained that the things to watch for now are dry mouth, mouth sores, skin rashes, dry eyes. He told the patient and caregiver that he would like them to keep an eye on these things and let the team know if they happen. “If they’re not too bad we’ll

likely continue with the taper, but we might need to hold off the taper for a while if we need to,” he explained. He added that these are important, though it isn’t his intention to be negative. He congratulated the patient on the biopsy results. After the physician left, the patient asked the extender if the mouth sores could come back. The extender confirmed that the patient may get mouth sores, and reiterated that with the Tacro taper it is possible that some GVHD will happen. The extender noted that they would watch, and if they see any of that they can slow down the taper.

Note from the excerpt above that Mr. Collins’ physician shows hesitation when he seems to put too much emphasis on the biopsy. The physician points out the same problem noted by Mrs. Kelly and all the other clinicians I talked with, which is that the negative biopsy does not necessarily mean the disease will not come back or that serious complications – particularly chronic GVHD – will not emerge. The physician then explains the kinds of symptoms the patient and the caregiver must watch for and report to the clinic. The physician’s response sensitizes the patient to potential complications (mouth sores), and prompts him to confirm this with the extender. The extender reinforces the information provided by the physician. Hence, while the good biopsy results are acknowledged, both clinicians work to ensure that the patient and caregiver do not stop “working at it.” On the other hand, Mr. Collins’ response suggests that he is not aware of the clinician perspective – hence the misalignment – and that there is a need for re-orientation as the timemarker approaches. Essentially, the conceptualizations of illness need to be reconciled, and the meaning of it re-negotiated.

Mrs. Johnson – an extender – stated that she feels day 100 gives a false sense of security to patients and caregivers. This is worrisome because if patients wait to report symptoms, thinking that a week or a few weeks would not make much of a difference, complications can get out of hand and very difficult to resolve – perhaps even irreversible. She said that this tends to be a concern especially with younger patients, who sometimes think that a little delay would not matter. The patients may also expose themselves to risks; for example, if they relax infection precautions more than warranted. I observed that there is a constant struggle – a tug-of-war of sorts – at clinic visits as patients negotiate freedom to do more activities: going on a boat, hunting, traveling, swimming, doing outdoors work, eating various kinds of foods, and so on. Managing expectations and clinical oversight becomes hard work. These observations, as well as clinician comments, suggest

that the misalignment between patient/caregiver and clinician perspectives at this transitional period could in fact lead to a crisis situation later for the patient and caregiver. Hence, it is imperative to organize information work earlier in the transplant process, and then reinforce the information as a patient approaches the transition, to raise awareness early on and prevent situations downstream that may arise from patient and caregiver negligence.

In summary, whereas the clinicians approach the problem of day 100 based on their professional knowledge and experience with managing the illness trajectories of BMT patients, from the perspectives of patients and caregivers the period around day 100 is unmistakably transitional, unless ongoing complications inherently make it clear to them that recovery will be a long-term process. In effect, the transition means multiple changes for them, most of which they consider to be in the positive direction. A negative biopsy, being able to go home, increased freedom in activities, looser clinical oversight, and even transitioning from being seen over at the infusion area of the clinic to being seen in regular exam rooms at clinic visits are all taken as indications of getting better. Their idea of where they are in the transplant process – or as they see it, where they are in the patient’s recovery – is markedly different from that of the clinicians. This is critical, as it can be dangerous unless the patients and caregivers are effectively reoriented to the next stage following the transition. They still need to know what to look for, and how to manage their daily lives to minimize risks. As noted earlier, clinic observations suggest that patients often have confusion about what the transition actually means for them in terms of their freedom to do certain activities, and they need some education on chronic GVHD at this point. It is also important to prevent the misalignment from being exacerbated in the cases of patients for whom certain restrictions are relaxed earlier than day 100. In those cases, decision-making is “intensely subjective,” as noted by Dr. Matthews. At the same time, clinicians’ personalized assessments are often different from patients’ and caregivers’ own interpretations of changes as indicators of getting better. For instance, a patient and caregiver may seem to be compliant with their medications and overall treatment, and therefore given more flexibility, but they still need to know what the transition means for them.

6.3.3. Case 3: Transition out of BMT

In this section, I describe a significant temporal misalignment associated with a critical transition in BMT: the transition of patient care from BMT clinicians. I show that, in part due to fundamental differences in the underlying temporalities that guide patients/caregivers and clinicians in determining a patient's readiness for the transition, all participants face difficulties with the transition process. In order to explain the misalignment clearly, I first describe in considerable detail what the transition process involves for the different participants – how it is experienced and provisioned.

In BMT, the goal is to eventually transition patient care to a primary care physician (PCP) and hematology-oncology (hem-onc) specialist, with the exception of the management of chronic issues directly related to transplant (i.e. primarily chronic GVHD). BMT clinicians often prefer to delegate aspects of patient care to PCPs during the transplant process. As detailed below, the timing of when the clinicians initiate this transition usually varies by physician preference. On the other hand, the ideal scenario is that a hem-onc specialist follows a patient for a few years regarding the original disease, after which patient care transitions entirely to a PCP. Besides the transition that is associated with recovery from transplant, hematology-oncology specialists treat BMT patients if their original diseases require maintenance chemotherapy following transplant or if there is disease relapse. In this section I focus on a misalignment concerning the transition, rather than the co-management of patient cases due to maintenance therapy or disease relapse.

A complex and interrelated set of challenges complicates the transition of patient care from BMT, making the transition difficult for patients and caregivers, BMT clinicians, as well as physicians on the receiving end of the transition (Büyüktür & Ackerman, 2014). A central cause for the difficulty is a temporal misalignment between how patients and caregivers experience the transition and how BMT clinicians envision and provision it. As illustrated below, for many patients and caregivers the transition is a process – often an extended one – with a significant psychosocial component associated with feelings of

readiness to delegate aspects of care to non-BMT clinicians. As I will describe further, the feeling of readiness – or lack thereof – is in part related to the strong relationships formed with the BMT clinicians as the clinicians work to manage the patients' illness trajectories according to the demands of disease time. In comparison to the patient and caregiver perspective, BMT clinicians tend to assess a patient's readiness to delegate aspects of patient care to a PCP based on a combination of disease time and their own personal judgment, with considerable practice variation in how different physicians oversee the transition.

First, I examine the patient and caregiver perspective in more detail. Their partnerships in care with the BMT clinicians last for at least a year, in many cases longer. During that time, the patients and caregivers are in difficult and vulnerable circumstances. Due to the arduous process and having come to transplant with little, if any, knowledge of what it involves, they grow to depend on their BMT clinicians for their medical expertise and emotional support. Consider Mr. Scott's case as an example:

Mr. Scott had an allo transplant for an acute form of leukemia. He developed acute GVHD in the digestive tract, which was treated. Skin GVHD also emerged early on and later became a chronic issue. A number of different infections brought him back to the hospital in the post-transplant phase. In all, he was readmitted to the hospital eight times for various complications. He had picc lines and NeoStar ports (i.e. surgically inserted central catheters) removed and replaced several times due to blood clots and infections. Mrs. Scott, his wife and primary caregiver, stated that after the transplant her husband barely ate and would sleep almost continually, which lasted for months. At the time of his interview that took place sixteen months post-transplant, Mr. Scott's ongoing problems included chronic GVHD of the skin, eyes, and mouth. He had significant dental issues that were caused by the dryness due to chronic mouth GVHD. At an earlier point in the process he had had narrowing in his esophagus as well, also from GVHD, and had undergone a procedure to address the stricture. However, in his interview, Mr. Scott stated that he feels food still gets stuck and he has to swallow really hard. He also noted that he has not really "got his taste buds back" since the transplant. When asked whether

he could eat everything at that point, he said he eats “because I gotta eat” and “because I remember what it used to taste like.” Although he was much more active in the house compared to how he had been in the first few months post-transplant (for example, helping with dishes and mowing the lawn), energy-wise he still had some trouble climbing stairs. Moreover, the physical issues aside, the most striking thing for Mrs. Scott was that Mr. Scott had changed personally after the transplant. She noted that, “His humor was changed. His way of doing things changed. His tolerance for things changed.” Mr. Scott agreed, adding that he has become much more sensitive and cautious in stark contrast to his previously laid back and fun-loving attitude.

As her husband went through the grueling post-transplant process laden with complications, Mrs. Scott frequently called the BMT clinic with questions or concerns:

“I called because I was always so worried about what was going on, you know. So anything that came up that I couldn’t explain away or do, or anything with medications. I just called. I always called. And they are wonderful when you call. And they call back – I mean, cause you always have to leave a message, and the girls put them through, and I mean they would always call me back really quickly.”

Mrs. Scott stated that she called the clinic when Mr. Scott was feeling too tired (“sleeping 20 out of 24 hours a day”), she called when he developed a fever, and she called when his legs started to swell from the steroids used to treat his GVHD. She called for “pretty much everything,” noting that the “phone relationship” with the clinic was intense. She explained that their BMT team had encouraged them to call:

“And they told me, you know. Call! So I took them at their word. You know I didn’t, I tried not to make a nuisance out of myself, but if there was something I didn’t understand or couldn’t explain I just called them. And they would either explain it to me or tell me all was okay and we could wait till the next visit, or ‘get him down here!’”

Based on comments in the clinic’s teamroom by members of Mr. Scott’s physician’s team, Mrs. Scott is viewed as a good caregiver among BMT clinicians. Frequent calls such as hers are expected – in fact, BMT clinicians, starting at the first transplant consultation appointment and particularly through the first few months of the transplant process, actively encourage calls for questions and concerns. At clinic visits and in phone

encounters, “call us if you have any questions,” “call us if you need anything,” or “call us if anything comes up,” are oftentimes their parting words to patients and caregivers. The clinicians also readily emphasize their accessibility. For instance, at a clinic visit about a month after his transplant, Mr. Simon’s physician extender encouraged him not to hesitate to call the clinic for any issues, noting that his team would see him if a concern emerged: “We’re here. We won’t be like, we’re booked we can’t see you. We’re always here.” Many patients and caregivers, like Mrs. Scott quoted earlier, take their BMT clinicians at their word. The clinicians’ accessibility, combined with the fear associated with potential complications, results in strong patient and caregiver reliance on the clinicians. Mr. Scott, for instance, noted that his wife was constantly worried about him between clinic visits, and it didn’t help that he kept having different issues creep up. Mrs. Scott agreed, saying that she had come to rely on their BMT physician so much that she literally counted the days to when they would next see him at the clinic:

“I was so scared every time that I wouldn’t be able to take care of [my husband]. We relied on Dr. Matthews. We could make it just so long and I would go, well we’re gonna see him in two days. And, well, we’re gonna see him in three days. You know? Now this last time it was a month and we got down to now and [my husband] started breaking out all this stuff and it’s like, okay we’re going down in three days. So yeah, now we’re at six weeks and I’m like, am I gonna be able to do six weeks without seeing Dr. Matthews? I know he’s only a phone call away but...”

Mr. and Mrs. Scott’s descriptions of their experience show that they have come to rely on their BMT clinicians, that they depend on their expertise, and that they have developed close relationships with them. Based on clinic observations and interviews, this is typical for patients and caregivers, who also become emotionally attached to their clinicians. For example, Mr. Smith – a patient – said to his clinicians during a clinic visit, “You are family.” Another patient, Mrs. Thompson, held her physician’s hands as he was leaving the exam room, telling him how much he was appreciated. Mrs. Isles embraced her physician at the completion of a visit. Mr. Perry told his physician extender that he considers him a friend. The extent of gratitude the patients and caregivers feel and the close relationships they have with their BMT clinicians are also evident from the many thoughtful gestures they make. As described earlier, they often bring home-baked cookies and cakes as presents, and photo albums that they show their clinicians. They have their

pictures taken with members of their clinician team and gift these to them. They share news about newborns in their families and ask about updates on the clinicians' children. These relationships are fostered through difficult times during the lengthy transplant process.

While clinic observations clearly show that their relationships with the patients and caregivers are also special for the BMT clinicians (for example, as evidenced from their reactions to happy and sad news concerning their patients), the clinicians do want – and need – patient care to eventually transition to PCPs and hematology-oncology specialists. The patients' and caregivers' reliance on them ultimately poses a major difficulty. In Mr. and Mrs. Scott's case, a sign of this difficulty surfaced at a clinic visit approximately nine months post-transplant when their BMT physician asked the couple whether they had a primary care physician with whom they were comfortable working. Dr. Matthews, the couple's BMT physician, explained that a time would come when hopefully they would not need to see him regularly anymore, and that they should have someone to follow Mr. Scott's care moving forward. Always pleasant and on good terms with Dr. Matthews, Mrs. Scott nevertheless responded fervently: "No! You're our physician! You did [the transplant] to us, you have to take care of us!" Mrs. Scott was smiling as she said this, and she was talking amiably, but there was no question that she was reluctant to move on to a different physician. In the interview that took place about seven months later, I reminded Mr. and Mrs. Scott of this instance and asked about their feelings concerning transitioning out of BMT. Mrs. Scott smiled and explained that she associated the transition with Mr. Scott getting better – importantly, at least in some respects getting to be like any other person who has not had a transplant. Once Mr. Scott transitions from his BMT team's care, it will mean to the couple that he has overcome major hurdles related to transplant and that his condition has stabilized. Even though he might continue to have chronic issues, these will be under control and he will have reached his "new normal." In the interview, Mrs. Scott indicated that she was now more open to the idea of the transition, especially since the couple has a primary care physician whom they trust and who tried to remain engaged by reviewing the information sent to him by the BMT clinicians. One can see that Mrs. Scott was going through a process, whereby her level of

comfort with the idea of the transition was continuing to increase over time. This is consistent with observations of patient and caregiver experiences with the transition; other patients and caregivers go through a similar process.

A significant part of this process for patients and caregivers involves the recognition that *transplant* is not responsible for all patient issues. Mr. Douglas, a BMT patient interviewed at about two years post-transplant, noted that for him this awareness came in a moment of realization several months after his transplant. It had not occurred to him that a problem might be unrelated to transplant until his BMT physician told him and the emergency room team that a neurologist must treat him for a case of paralysis:

“I woke up one morning and my face was paralyzed. So my wife took me to the emergency room and we sat there for a while. [My BMT physician] happened to be on the floor doing rounds and they called him down to the emergency room, and he said why did you call me for a neurological problem? Oh, okay. Wake up. That was the moment. Okay, not everything that happens or is going to happen to me is going to be related to the transplant or a side effect of the medications. Until that point in time everything that had happened to me health-wise we could trace back to a side effect or an effect of the transplant. I got CMV²⁶ because my immune system was suppressed. I got infections because the ports were there. You know? It’s all traceable back to the transplant one way or another. So that kind of woke me up.”

In his interview Mr. Douglas stated that, although he feels comfortable now, it had taken him a while to feel comfortable enough to make decisions regarding whom to call for a health issue – his BMT physician or his PCP. Not all patients reach this level of comfort easily. Mr. Dorsey, for instance, turned up at the clinic one day – he did not have a scheduled appointment – asking to see someone on his clinician team because he believed that he had gotten skin cancer. He wanted a clinician to take a look at his skin. This genuinely surprised and confused the BMT clinicians in the teamroom who heard his request from a staff member, because they all expected Mr. Dorsey to go to a PCP in order to get a referral to a dermatologist for this concern. From a patient’s standpoint however, it is possible to get confused if problems are generally linked to transplant (as was also the case with Mr. Douglas, quoted above, earlier in the transplant process). BMT clinicians regularly identify skin cancer as the most common secondary cancer following transplant, and urge their patients to watch for it. In a conversation that took

²⁶ A viral infection

place after he came to the clinic asking to see one of his clinicians, Mr. Dorsey told me that he associated skin cancer with his transplant. Therefore, even though a BMT physician would not be the one to treat this complication, BMT was the first place he thought of contacting. Like Mr. Douglas and Mr. Dorsey, many patients have difficulty dissociating their various health concerns from their transplants, or even from the medications prescribed to them at the BMT clinic. Mrs. Leeder – a physician extender – noted that patients sometimes say that their issues are happening because of some of their medications, and consequently hold BMT responsible for their care. Consequently, the patients and caregivers often feel blindsided when they are asked to see clinicians other than their BMT team for various health issues.

Mrs. Leeder said that she has had patients “who got upset or cried” when told they should see their PCP for a problem. She explained that some patients feel their BMT clinicians are “abandoning” them when they are asked to see a non-BMT clinician. This is the case even for some patients whose transplant-related issues have resolved. For instance, a patient whom Mrs. Leeder followed for a very long time was able to get off all immunosuppressive medication and was only on three medications otherwise (i.e. he was doing very well from the medical standpoint), yet he got very upset when he was told that he should start seeing a PCP. The patient told her that he “didn’t see this coming” and thought that his BMT team was trying to “get rid of” him. Whether the patients – or caregivers – respond this strongly or with a more controlled disinclination, the BMT clinicians in general have a difficult time reassuring them that they are ready to work with PCPs on health issues unrelated to transplant. I have observed that patients anywhere from a few years to ten years out from transplant continue to request from their BMT clinicians anything from flu shots to anti-depressants.

This reliance and emotional attachment by patients and caregivers is a significant issue for the BMT clinicians. The clinicians feel many patients come to expect that BMT will address most or all of their health problems, not just those related to transplant. Two physician extenders noted that their patients ask them to run all sorts of tests, such as hormone levels, the results of which could be better addressed by other specialists. As

discussed earlier, this expectation is in part due to the nature of the BMT process, since the clinicians end up having to do a lot of “handholding” – as one of the extenders described it – and the patients get used to it. For instance, Mrs. Tanner – a patient – continued to experience a number of chronic issues four and a half years post-transplant, and noted that she still finds it difficult to decide whom to call, the BMT clinic or her PCP, with a question. She described her indecisiveness regarding whom to call and her hesitation to leave the care of her BMT clinicians as follows:

“That’s tough right now. That is tough right now. Cause we’re – you’re like a, like a 19 year-old leaves the house. You don’t know whether to lean on your roommate or to lean on your parents. And that’s how it feels right now. You’re scared to get away from your parents and every now and then you lean more and more and more on your roommate.”

In the quote above, Mrs. Tanner is referring to the BMT clinicians as “the parents” and her PCP as “the roommate” in order to explain that she does not yet feel comfortable leaving the care of her BMT team. The fact that she describes the situation as “every now and then you lean more and more and more on your roommate” indicates that she also experiences the transition as a process. Mrs. Tanner explained how her BMT team was trying to reassure her that a PCP could now follow her for many of her health issues. Her own PCP, with whom she has a pre-established relationship dating prior to transplant, which she described to be as excellent, had also assured her that he would take care of her and refer her to BMT for any transplant-related issue he could not manage. Still, Mrs. Tanner explained that she was not yet ready to move on with the transition:

“I feel like I’m being a bother [with the BMT clinic], but I don’t know what else to do. When I told [my BMT nurse] this, I said I feel like I’m being a bother, she says this is natural. Because you’re breaking away from the womb again, basically. You’re breaking away. It’s natural to be that way. She says, you know you’re in remission, you’re – she’s just trying to build the confidence. That’s what it’s taking. ...[Yet] if I ... feel I need to contact [the BMT clinic] I do not hesitate. I’m not there yet. I’m getting there.”

Through the quote above, we again see a critical issue for patients – and caregivers – in the transition: Mrs. Tanner recognizes that the transition is a process. A patient must recognize that she or he should delegate aspects of her or his care; this comes in a moment of realization, as in Mr. Douglas’ experience with his face paralysis, or through the encouragement and urging of BMT clinicians, as with Mrs. Tanner. But to borrow

Mrs. Tanner's description, the patients feel that they need "to get there." As such, this is a process that is not solely based on feeling well physically. Seven years out of transplant, Mr. Langdon still noted that coming to clinic every six months for follow-up was comforting to him, although he did not have any significant chronic issues. He said, "Just having the doctor look at the screen you know, and tell me that they (i.e. the blood counts) look good. I like to hear it from him."

Overall, patient and caregiver accounts reveal that the transition to non-BMT physicians is experienced as a process with a significant psychosocial component. As discussed above, the psychosocial aspects – feelings of readiness to delegate aspects of care to PCPs and hem-onc specialists – are in large part associated with fear of complications, the tendency to see all health concerns as related to transplant, and the strong relationships that are cultivated with the BMT clinicians. However, a closer analysis of these issues suggests a connection with the way in which the BMT process is overseen based on clinician concerns of acute complications. An important reason behind the ready accessibility of BMT clinicians to patients and caregivers, particularly in the first few months of outpatient care, and why they actively encourage the patients and caregivers to call the BMT clinic "for anything suspicious, even if it seems to be something small," is the fact that acute issues – generally associated with the first 100 days post-transplant – must be identified and addressed before they get rapidly out of control. The clinicians necessarily rely on the patients and caregivers to alert them to any emerging symptoms, and suspicious or concerning changes. It is crucial that these are reported to the clinicians immediately, so that the necessary interventions can be made in a timely manner. The clinicians do not want the patients and caregivers to delay reporting any issues, such as waiting for the next scheduled clinic visit. Hence, they constantly remind the patients and caregivers to call the clinic, and make statements regarding their availability. Dr. Erickson, a BMT physician, noted that for this reason they – the BMT clinicians – are partially responsible for making the later transition difficult: "The problem is that *we* 'train' them,"²⁷ he said, referring to the fact that the patients and caregivers are habitually encouraged to call the BMT clinic. While this "training" plays a critical role in the

²⁷Emphasis original.

management of illness, it is then relatively difficult to “re-train” the patients and caregivers to eventually let go of their BMT clinicians and make the transition.

While BMT clinicians recognize this issue, their criteria for the transition are different. It should be noted that there is considerable practice variation regarding when different BMT physicians or their team members ask their patients to get back in touch with PCPs or hematology-oncology physicians. Some BMT physicians prefer that their patients (re)establish contact with a primary care physician as early as around the day 100 transition, or the latest at six months post-transplant, and transfer aspects of patient care as soon as possible. Other BMT physicians reason that a patient does not have to see another physician while still having active issues from transplant, and coming for visits at the BMT clinic fairly frequently. In a third perspective, some BMT physicians are reluctant to transition their patients for the most part unless they meet the ideal scenario, which is that the patient should be off all immunosuppression with no active GVHD, or on minimal immunosuppression with all GVHD under control. Hence, there is considerable variation in physician preference and no common process by which the transition occurs in the clinic setting. However, whatever a particular physician’s preference is, a patient’s readiness for the transition – or at least the initiation of the transition via establishing contact with a PCP – is primarily determined based on disease time and the physician’s personal assessment of the patient’s situation. For instance, as described in detail earlier, day 100 and six months post-transplant are timemarkers in the transplant process (for acute complications and the best-case scenario for being off immunosuppression, respectively), which some physicians use to recommend their patients to re(establish) contact with a PCP. The clinicians who wait for active issues to resolve or for the patient to be off of or on minimal immunosuppression are also using disease-based and personalized heuristics in determining an appropriate point in time to initiate the transition. Hence, the temporality of the transition is gauged in different ways by the clinicians in comparison to the patients and caregivers.

For BMT patients and their caregivers, the time blocks that are connected by the transition have particular characteristics. In the first time block, there is much concern

with transplant-related (potential) complications and a heavy reliance on the BMT teams. In the time block that follows, there is reassurance regarding the patient's stability and confidence regarding the patient's – and caregiver's – ability to recognize issues and to direct them to a clinician appropriately. Unlike other transitions however, the transition between these time blocks tends to be rather extended in the experiences of many patients and caregivers. As transitions generally do, it also requires significant re-orientation, including an important psychosocial one, although there are certainly exceptions. For instance, some non-local patients and caregivers prefer to see a PCP for some health issues, because they then do not have to travel long distances to the BMT clinic. However, in my observations, they tend to be the minority. Even patients who live several hours from the BMT clinic – such as Ms. Lauren, who travels two hours to get to the hospital – often prefer the care of their BMT clinicians, and have difficulty with the idea of the transition. On the other hand, it is natural that the BMT clinicians envision the transition less as an elongated process, because they feel confident that the patients are ready to take the next step from the medical viewpoint. Mr. Lawrence – a caregiver – joked that his wife's BMT clinicians had to eventually “wean them off” from their care, because they were scared to work with other clinicians. His reference to a gradual transition, however, may in fact point to an effective strategy to help with the transition of patient care from BMT.

6.4. Temporalities in Illness

In this chapter, I described the different ways in which BMT patients and caregivers experience and envision a transplant trajectory from a temporal perspective. As detailed, the main temporal features include crises, time blocks that are separated by transitions, and temporal knots where expected trajectories do not match the realities of illness. It is important to note that, in the management of illness, these temporal experiences, along with those associated with diseases, treatments, the human body, and personalized assessments of where a patient is with regards to illness, are not truly exclusive to one group of participants – such as patients, caregivers, or clinicians. In practice, these temporalities can be experienced in different ways by different participants in different

circumstances, creating or modifying various misalignments with practical implications for the management of an illness trajectory.

Consider, for instance, patients who are afraid of leaving the hospital. For the clinicians who oversee these cases, the patients are ready to make a transition (to move from one time block to another following hospital discharge) from the medical viewpoint, whereas the patients feel that they need more time to recover from illness. Awareness of such a misalignment provides clinicians with additional information about a patient's condition (as patient self-assessments, as well as caregiver assessments, are deemed important), and often prompts them to give additional psychosocial support as well. On the other hand, it is possible to envision a situation in which a clinician might feel that a patient could remain on the ward longer, whereas demands related to institutional temporalities – such as overcrowding and the turnover of hospital beds – might not allow for this to happen. Such situations involve misalignments between disease time, institutional time, and experiences of time blocks and transitions.

It is also possible that clinicians will feel there is more of a crisis situation while the patients and caregivers do not. For instance, based on their professional knowledge, certain symptoms tend to alarm clinicians much more than they do the patients who experience these. Patients who believe they are in a stable time block or feel that they are doing well sometimes have concerning issues, the symptoms of which they disregard or underestimate. In BMT, an example of this is shortness of breath (often mild in the beginning), especially in the period after day 100, sometimes readily attributed to ongoing fatigue and loss of stamina by patients. Clinicians who fear that there is lung GVHD, which they know to be particularly dangerous, feel there is a critical situation (particularly if it remains unaddressed), whereas the patients sometimes have to be convinced that there is something potentially serious going on. I provide a specific example of this in the next chapter, where a physician had to spend considerable effort to convince a patient that he should take lung GVHD seriously. Similarly, a different BMT patient's clinic nurse and BMT physician got alarmed by the symptoms that the patient's wife reported on the phone, which suggested he might have GVHD in the digestive tract,

and urged the patient to come to clinic immediately. Although he finally did come in, it took several follow-up phone calls and many explanations by the patient's clinic nurse to get him there. In the meantime, the clinic nurse and BMT physician were concerned enough to discuss the situation in the teamroom as a potential crisis for the patient.

Finally, it is possible that clinicians experience certain issues as temporal knots, where the realities of the situation do not align with their expectations. For example, in the previous section I discussed misalignments associated with the transition from BMT. This misalignment itself is a temporal knot for the BMT clinicians, as they are unable to readily persuade the patients and caregivers to begin the transition. The transition often does not happen when the clinicians would like and expect it to happen, leading to ongoing efforts further along the process, and in some cases situations where patients several years out of transplant do not even have a physician to assume follow-up care.

6.5. Temporal Alignment in the Management of Illness Trajectories

Temporalities of various kinds influence the experience of illness and organize patient care in both clinical and non-clinical settings. Examining these is important for understanding and managing trajectory work (Strauss et al., 1997), including information work. In this chapter, I focused on the different ways in which patients and clinicians experience and envision time, particularly with respect to transplant trajectories. It is important to note that other temporalities affect experiences and patient care in numerous ways, and at different temporal scales. For instance, the cyclic organizations of clinic work (e.g. clinic days of BMT physician teams) and patient work (e.g. daily medication routines) influence the structure and pace of trajectory work. Temporalities associated with infrastructure (e.g. the machine time of diagnostic equipment, such as an MRI or PET scan) and personal biographies (e.g. whether a patient is working or retired, has young children or not, or a physician's balance of patient care with research and administrative work) all shape patient, caregiver, and clinician time and work (Jackson et al., 2011). It is essential to recognize and examine the different temporalities that

collectively influence patient care, as well as how they interact with one another, align or misalign in significant ways that have practical implications.

Temporalities – in fact, composites of various underlying temporalities – and information interact in important ways. The implications of temporal alignment and misalignment from the perspective of information work can be multiple: patient education, clinician-patient-caregiver communication, collaborative work in clinical settings, management of psychosocial issues in patient care, and the design of healthcare technologies are all areas in which temporalities matter. For instance, understanding a patient's temporal experience of illness can help clinicians in designing and implementing information interventions at critical junctures to help the patients and caregivers become more comfortable and effective in health management, or perhaps more compliant and cooperative partners in care. In BMT this could mean repeating and reinforcing information at key points following crises, the provision of transitional periods, or the prevention, identification and/or management of temporal knots. A patient's understanding of a BMT clinician's temporal perspective may prevent unrealistic expectations and consequent psychosocial responses. Temporalities matter, and add another meaning to the idea of 'being on the same page' in clinician-patient-caregiver partnerships.

An examination of temporal features in the BMT context shows that what patients and caregivers need to learn and apply is not limited to disease and treatment-related knowledge. They must also learn how to navigate this particular medical world. Moreover, because psychosocial issues can arise from unmet or unrealistic expectations regarding illness trajectories, patients and caregivers must also monitor and address emotional or mental responses. In all of these areas, it's through their collaborative work with the clinicians that they gradually gain expertise within the BMT world – particularly within the world of this BMT unit. The clinicians undertake particular information work to guide their patients and the caregivers in this process. The timing of the information work is important to produce desired outcomes. In the next chapter I examine one kind of information work – scaffolding – that is thus used in trajectory management.

Chapter 7

Navigating the Transplant Trajectory Via Scaffolding

Shaping, managing, and experiencing the trajectory of an illness are fundamentally social and collaborative endeavors (Strauss et al., 1997). The clinical staff, the patient, and other interested parties – such as the patient’s caregiver and kin – comprise the key participants. As detailed in the literature review, the co-construction of an illness trajectory involves many different types of work, such as machine work, safety work, and articulation work – among others – by the clinicians (Strauss et al., 1997), and both illness and everyday life work by patients and caregivers (Corbin & Strauss, 1985). In this chapter, I focus on information work. In particular, I describe four key areas in which information work is essential for the patients and caregivers in BMT to develop and apply the necessary knowledge to effectively manage their care and health. Time features prominently in this discussion, as the temporal perspectives of the participants and temporalities in the clinical context are among the principal contextual factors that affect information work and make these effective. A key factor has to do with providing, receiving, processing, and responding to information when it is practically germane, that is *information-in-time*.

In bone marrow transplant, the high degree of complexity involved in the treatment, the lengthy nature of the process, the uniqueness of each patient case, and contextual factors – including the temporal perspectives and experiences of the patients and caregivers – render information-in-time particularly important. The practice allows leverage to clinicians in shaping and managing the illness trajectory, as well as aspects of how it is experienced, by teaching and reinforcing important matters. It also empowers patients and caregivers in terms of taking informed action. Essentially, information-in-time is the means by which the state of care and the definition of that state is co-constructed by the patient, caregiver, clinicians, and other interested parties.

7.1. Information Work in BMT

“I had literature from a friend and we were not wanting to look into that kind of stuff because it’s kinda, it’s a lot of negative. Right? You read that stuff and it was a lot of, well this could happen and that could happen and this. So we choose not to do that. We try to stay as positive as we can. But after four and a half years, and the education that you get in four and a half years of GVHD and the pneumonias, and, um, just the medications. You know, how you get information about, um, they call it, like an AIDS patient – when you’re immunosuppressed. When you’re immunosuppressed, a lot of the things that you get, you don’t realize that you’re even in a negative situation until you get [these]. And the doctor would say, okay you need to stay away from this and be careful of that, be careful of this. And then you come back to what I said yesterday, you’re always trying to get your, you’re so new into it, that you just can’t shut yourself off. And so it’s trying, especially a guy like me, so you keep on trying to get back to the guy you were and it’s not gonna happen. And it takes a while to get a hold of that. And so, I guess to answer your question, it’s an ongoing education. It’s a continual, ongoing education.”

Like Mr. Roberts quoted above, the BMT patients and caregivers in this study have consistently indicated that learning is an ongoing process in transplant. They develop most of their knowledge in context, as things actually happen to them, through both corresponding information work by their clinicians and their own experiences and actions, all of which are also interdependent. The information work involved in this learning can be viewed in terms of *scaffolding* (Pea, 2004), a concept from the education literature. Scaffolding involves gaining new knowledge and skills in an unfamiliar context in which experts – in this case, clinicians and other professionals, such as social workers – must provide guidance, enabling the learner to develop increasing knowledge and competence within that context. At the same time, in the context of this study, the scaffolding is *reciprocal* (Holton & Clarke, 2006), because the patients and caregivers have their own expertise, information and knowledge, and they actively probe, collaborate and negotiate in the learning process. New knowledge and skills are internalized and applied in communicating with the clinicians, making decisions, and managing illness.

Clinic observations and interviews show that knowing enough to effectively and comfortably manage one’s care and health involves much more than being knowledgeable about diseases, symptoms, and treatments. Navigating illness and the transplant process require different types of knowledge and their application to patient

care and daily life. There are at least four different areas in which patients and caregivers must develop a certain amount of familiarity and expertise, and BMT clinicians engage in information work to help them in these areas. The four critical areas are: (1) Diseases and treatments, (2) institutional processes, (3) social interaction, and (4) emotional responses. Next, I briefly describe each of these in the BMT context, showing that the timing of information work is crucial and in some respects follows predictable temporal patterns.

7.1.1. Disease and Treatment Scaffolding

Diseases and treatments are the most palpable areas in which scaffolding is essential. BMT patients and their caregivers must have a sufficient understanding of the relevant diseases – including those they must watch for – as well as corresponding treatments in order to fulfill their own responsibilities of observation (of symptoms and changes), prevention, and correct implementation of interventions. BMT clinicians engage in this type of scaffolding from the very beginning of a patient’s transplant trajectory. This type of information work is generally more intense in the first few months post-transplant, although it continues throughout the process.

As described in the previous chapter, BMT patients and caregivers have a very difficult time with the information and instruction provided to them in the pre-transplant period. In part due to the immediate crisis situation and information overload, information pertaining to other phases of the transplant process (and particularly to diseases and interventions in the post-transplant period) is particularly difficult to absorb, process, and learn. Consequently, they rather focus on practical information – such as making housing arrangements or putting their affairs in order – that is of priority. Hence, the patients do not remember much at the time they move into the transplant hospitalization. Essentially, the initial crisis situation causes the need for downstream scaffolding. At the same time, treatment-related information provided in the pre-transplant period is relatively broad and out of experiential context. Observations of post-transplant clinic visits show that patients and caregivers learn – in much more detail – as their transplant trajectories unfold and

particular information becomes more immediately relevant. This has to do with information-in-time.

The following is a simple example of how a patient and caregiver learn in context. As noted earlier, information about acute GVHD is included in standard pre-transplant patient education. A patient's BMT physician and transplant coordinator both discuss GVHD, including its common manifestations. However, it is not until the possibility of GVHD becomes salient – by timing or the emergence of symptoms – that the patients and caregivers need more specifics, and begin to ask detailed questions for the purpose of being informed. Consider the following excerpt, which relates the first time a BMT clinician discussed acute GVHD of the skin with Mr. Harris and his caregiver at a post-transplant clinic visit not long after his discharge from the transplant hospitalization:

Looking over at the patient, the extender asked the caregiver if his face seems a little red. The caregiver laughed, saying that she could not really tell since the patient lost his hair; the subtle contrast in color makes it difficult for her to judge changes. Commenting that perhaps the patient's ears are also a little red, the extender asked the patient to pull up his shirt to see if there is redness anywhere else. Lightly pressing on the skin the extender said perhaps there is a little bit in the belly area as well. "I wonder if you have a little bit of GVHD going," the extender commented, adding that the slight color could also be from the magnesium infusion the patient was getting, explaining to the couple that the infusion can make people flush. The extender then urged them to make sure to call the clinic if they see a rash emerging. The caregiver asked, "What does a rash look like?" The extender explained that the rash would look red, perhaps even a bit like sunburn, and that it could then spread. It could either be itchy or not. "Full body or more specific places?" asked the caregiver. The extender pointed at specific areas on the body, explaining that common places to watch are the face, neck, chest, and hands. However, the extender also added that the rash could show up anywhere.

In the excerpt above, note that the subject of GVHD was raised because the extender noticed a subtle coloration, particularly on Mr. Harris' face. The extender asked the caregiver if she thinks there is a slight color change from the normal, intending to draw on her familiarity with the patient, but the caregiver indicated that the changes associated with chemotherapy throw off her judgment a little bit. The extender stated the possibility of GVHD, but also provided a likely alternative explanation for the manifestation given the particular context (i.e. the patient was receiving magnesium infusion, which is known to cause flushes). Noting that it is still important to keep an eye on this, the extender instructed the couple to call the clinic if a rash emerges. This prompted the caregiver to

ask for more specific information about the kind of rash they should be looking for. The caregiver also followed up on the description the extender provided by asking about the potential location of a rash. Essentially, this was a “scaffolding moment” regarding the symptoms of a particular disease known to occur in the period of transplant in which this clinic visit took place. Moments like these are extremely common throughout the transplant process and information work covers a wide range of topics concerning various diseases, symptoms, treatments, medications, tests and procedures, transfusions and infusions, and so on.

Clinic observations also reveal a pattern of layered information over time. For example, *before* acute skin GVHD occurs, the patients and caregivers receive general information about how it would manifest. In these conversations with clinicians they often ask what the treatment would be if it does occur, otherwise the clinicians usually volunteer this information. The patients and caregivers are told that the treatment would be a steroid cream for mild GVHD, with the addition of systemic steroids in more severe cases. This is generally the level of detail provided at that point. At several clinic visits where acute skin GVHD was *newly diagnosed*, the physician specifically pointed out the affected areas (the clinicians calculate the percentage of the body that is covered as part of their own work) and sometimes asked the caregivers to take a closer look at the rashes, especially in cases where the GVHD was on the patients’ backs and therefore difficult for the patients to see. This is important in part to teach and to enable a caregiver to keep track of any changes in the rash, including how widespread it is, so that the clinicians are informed about these in a timely manner. In addition, the clinicians provide precise instruction regarding treatment. For example, about steroid creams the patients and caregivers are told that only a mild one (Hydrocortisone) should be used on the face, while a stronger steroid (e.g. Triamcinolone) should be used on affected areas on the rest of the body. Particularly the first time the medications are prescribed the clinicians reiterate that the stronger steroid should not be used on the face, and include directions in the patient instructions printed out at the end of clinic visits. The clinicians also recommend that a layer of regular moisturizing lotion be applied on top of the layer of steroid cream. If a steroid pill is prescribed, the clinicians provide precise instruction on

the dose and timing. At *subsequent* clinic visits, the patients and caregivers generally learn more about steroid tapers and how to recognize when the GVHD enters the “burnout phase” (i.e. when it starts to get better). Hence, scaffolding temporally parallels the unfolding of issues.

Over time the patients and caregivers tend to become quite good at recognizing when GVHD is flaring-up or burning out, and better understand how it is associated with changes in immunosuppression. Some of the patients and caregivers specifically showed me how their GVHD looked like, and talked confidently about affected areas that had a flare-up or where the GVHD was burning out. However, given the complexity of treatment, the clinicians often have to actively continue the scaffolding process. For instance, it is fairly common for patients to try to negotiate with the clinicians about steroid or Tacro tapers, because they are generally wary of the side effects. They do not always understand the intricacy involved in managing the tapers, and that seeing no change while on a medication does not necessarily mean that the medication is not having an effect. Over the study period there have been cases where the patients tampered with their immunosuppression, to the frustration – though not surprise – of the clinicians.

It is not only new knowledge that the patients and caregivers must gain to manage illness, but also new skills and the confidence to use these. For instance, in the previous chapter I described how caregivers are generally quite nervous about their responsibilities, especially ones that require manual skills, at the time of their patients’ transition to outpatient care. Tasks such as giving magnesium infusions, changing the dressing on a patient’s catheter, flushing the catheter, giving insulin shots, and so on, are scary and overwhelming at first. They receive some training on giving IVs and shots, and caring for the catheter, before hospital discharge following transplant. However, many of the patients and caregivers in this study confided that they were not comfortable enough using these skills at the beginning. On the other hand, a stepwise approach could help to build these types of skills as well. For example, besides the training they receive prior to hospital discharge, patients and caregivers usually have a home care nurse set up and administer the IV magnesium the first time this is done outside the hospital. Despite the

opportunity to observe a nurse administer the IV however, there is still significant uncertainty and even mistakes when they try to do it on their own. After explaining the difficulty he and his wife had with the magnesium infusion the first time they did it on their own (they had a problem with the set-up and the infusion was still running after nine hours, so they had to call the hospital in the early hours of the morning), Mr. Davis – a patient – stated that hands-on training would be helpful in developing these skills: “To do it is different than to have somebody tell you or even show you. You know, you got to do it yourself. It’s always, you know, what they say: You tell me I forget, I see I understand, I do I know. So, it’s pretty much the way that it was. You had to do it to know.” Indeed, the patients and caregivers reported that these types of tasks eventually “fell into a routine,” and often noted the expertise they developed in certain skills.

Clinic visits reveal that there are a number of strategies the BMT clinicians employ in scaffolding to help their patients and the caregivers learn about diseases and treatments. I categorize these as follows: clinicians *explain* (e.g. you shouldn’t drive because Tacro tends to affect reaction time), *show* (e.g. see how this area here is darker?), *quiz* (e.g. did we talk to you about GVHD? What do you remember about it?), *instruct or provide guidance* (e.g. try adding one food at a time so that you’ll know if you can’t tolerate one of them), *foreshadow* (e.g. we will do a slower taper at lower doses), *forewarn* (e.g. you might feel tired after this taper), *reinforce* (e.g. again, don’t use the Triamcinolone on your face, just the Hydrocortisone). Depending on the particular piece of information and the particular context – including temporal considerations – some strategies may be preferred over others. For instance, being aware of the information overload that patients and caregivers experience prior to transplant, Mrs. Taylor – a social worker – uses “quizzing” to assess whether or not they have gained basic knowledge sufficient enough to make an informed decision about transplant. It is helpful to “show” and “explain” each time a complication with visible symptoms emerges. “Foreshadowing” is beneficial to sensitize a patient and caregiver as the patient approaches a transitional period, or to prevent potential temporal knots. The clinicians often “forewarn” when there is the possibility that a patient may be re-hospitalized if complications unfold in a particular

manner, and so on. Hence, temporal considerations can significantly affect information work and may be used for optimizing some processes.

7.1.2. Institutional Scaffolding

In order to be able to manage illness and move through the transplant process effectively, it is necessary but not sufficient to gain knowledge and skills about pertinent diseases and treatments. Equally important is the ability to navigate the particular institutional structures in which patient care takes place. BMT patients and caregivers learn about these structures – routines and processes – primarily from their clinicians as their transplant trajectory unfolds. While the need for institutional scaffolding may arise in all phases of the transplant process, it is much more pronounced in the weeks following hospital discharge when a patient is first transitioning to outpatient post-transplant care, as well as in the course of transitioning patients out of BMT care. As mentioned briefly in the previous chapter, at the time of the transition from transplant hospitalization, the patients and caregivers have limited familiarity with the BMT clinic. Moreover, the clinic structure for post-transplant care is very different from that of pre-transplant care. As they transition into post-transplant care, the patients and caregivers begin to learn how the clinician teams operate, how internal processes and routines work, and how to communicate with the clinic, among other things.

Clinic observations and interviews reveal many examples of institutional scaffolding. Among the most essential of these are the ones associated with phone encounters with the clinic. As stated earlier, in BMT it is imperative for the patients and caregivers to report emerging symptoms and to ask questions about issues they are unsure of in a timely manner. This is especially important in the early post-transplant period since acute complications must be identified and treated as soon as possible. Thus, the clinicians urge their patients and the caregivers – repeatedly and persistently – to call the clinic for any questions or concerns they have. Such phone calls are extremely common and fulfill a critical role in patient care. The transition to outpatient care marks the beginning of the early period when phone calls are particularly important, and at first the patients and

caregivers are largely unfamiliar with the routines of the clinic. There are a number of aspects about phone encounters that they learn to effectively work within established clinic structures – for instance, how to contact the clinic, whom they talk to, what to do in the after hours, when to expect a return call, and so on. Next I illustrate why knowing these processes is important.

When a call is made to the clinic, a patient (or caregiver) does not directly reach the physician team. This is different from the pre-transplant experience, because the patient's main contact person at that time was a transplant coordinator and the patient had a direct phone line to the coordinator. In the post-transplant phase, a different staff member takes down the reason for the call and forwards it to the clinic nurse on the patient's physician team. After assessing the reason for the call (and consulting with the team's extender and/or physician as needed) the clinic nurse calls the patient back. The patient and caregiver learn that the nurse will return their phone call sometime in the course of the day, especially if the reason for the call is relatively urgent, and potentially the next day if there isn't much urgency. They must also learn that the clinic day ends at 4pm; hence, they will not receive a callback from their clinician team past that hour. At clinic visits early post-transplant, the clinicians sometimes refer to this process and recommend that the patient or caregiver call the clinic as early as possible during the day so that there is enough time for the nurse to process and return the call within the same day. The patient and caregiver also learn that the process for after hours (i.e. after 4pm) and weekends is different, and that it is likely they will not be talking to a clinician who is particularly trained in bone marrow transplant. Some patients learn by experience to avoid this as much as possible. For instance, a physician who took her after hour call told Mrs. Adams to take a painkiller which is on the list of painkillers BMT clinicians do not want their patients to take. On a related note, the clinicians have stated that receiving a call as early as possible in the day allows them to ask the patient to come over to the clinic if there is a potentially urgent matter. If it is late in the day and there isn't sufficient time to see the patient in clinic, the patient will have to go to the emergency room instead. This is preferred neither by patients and caregivers nor the clinicians, especially due to the highly specialized nature of BMT. Even if a patient needs to be re-admitted to the hospital

everyone prefers this to happen through the clinic, because then the patient will be admitted directly to the BMT ward. For example, Mr. Bell lives several hours away from the hospital. When suspicious symptoms emerged that suggested a possible case of late-onset acute GVHD, his clinic nurse had to urge him by phone to come to clinic immediately so that he could get there before 4pm, noting that he would likely be admitted to the hospital.

The clinic also has established routines for when to call a patient besides returning a particular phone call. This is sometimes a point of confusion until a clinician explains the process to a patient and caregiver. In the following excerpt from a clinic visit early in the post-transplant period, an extender explains one of the primary routines for when the clinic team calls a patient to Mr. Harris' caregiver:

The extender explained that sometimes microorganisms get into the lines [i.e. the catheter] and can get pushed in when the clinicians give things, such as a blood transfusion. So a nurse would take samples and they would check to see if there is anything [i.e. any microorganism] in the cultures. The caregiver asked whether they should call the clinic to get test results back. She said that last time they were expecting the result of a test but did not hear from the clinic, so they called to learn the result. She added that they were a little confused about when to call. The extender answered that the clinic would call them if something comes up positive in the blood cultures that they would take from the lines. "So you will call us?" the caregiver wanted to confirm. "If anything is positive," the extender answered, "then we will call and let you know, because we will probably need to put you on antibiotics." "So if we don't hear from you it means it's negative," said the caregiver. "Means nothing came up. We won't call you," confirmed the extender.

The routine that the extender explains to the caregiver in the excerpt above is the following: the clinic team calls a patient when there is a change to the treatment plan in place; otherwise everything stays the same. In the example above, not hearing from the clinic would mean no microorganisms were found in the blood cultures. The clinic would call only if an infection was identified and the patient needed antibiotics. The same reasoning is applied in other situations. A very common and critical example is how the clinicians manage the Tacro dose a patient is taking. When a patient comes for a clinic visit, the tests that are run include the Tacro level in the blood. BMT physicians want to keep the Tacro level within a particular range, and there are common toxic side effects at levels beyond the therapeutic range. The dose of the medication is adjusted based on the

test result. It is known that the Tacro level, unlike most other test results, does not come back from the laboratory for several hours; hence, usually it is not back at the time of the patient's clinic visit. Therefore, any changes to the medication dose cannot be decided during the visit. The routine is that the clinic will call the patient once the result gets in if the dose needs to be adjusted; otherwise the patient should continue taking the same dose. Since Tacro is a critical medication and the dose is adjusted fairly frequently based on these blood tests, it is essential that the patient and caregiver know this routine. Additionally, a related piece of knowledge that the patient and caregiver must have is that, for an accurate interpretation of the level, the patient should *not* take Tacro on the day of a clinic visit before getting blood drawn. Sometimes patients forget this. In the early days post-transplant the BMT clinicians frequently remind them to hold the Tacro until after the blood draw. Once they internalize the whole process, patients who forget sometimes remember on their own and self-report the mistake to their clinicians during their visits.

The examples provided above illustrate the importance of knowing the relevant institutional processes and routines to be able to co-manage patient care effectively with the clinicians. Much of this knowledge is about specific institutional arrangements; it is not possible to know these without having them explained. On the other hand, institutional arrangements are often based on underlying temporalities, such as the timing of ordering tests, or how long it takes for certain laboratory results to get back. BMT patients and caregivers are often keenly aware of the significance of this type of knowledge. Mrs. Martin – a caregiver – labeled it as being in a “learning curve” in an unfamiliar context. Learning happens over time, through experience and information-in-time. For instance, on hospital discharge following transplant and in the early days of outpatient post-transplant care, the patients and caregivers learn the process for home deliveries of IV magnesium and other supplies. They become familiarized with how the scheduling of visits, treatments, and referrals are done at the clinic. If a blood transfusion is needed and the timing of it is being discussed, they learn that a process called “type and screen” must be completed first to ensure compatibility between the patient's blood and that of the donor, and that this process takes time. Similarly, they learn that platelets

must be transfused prior to an upcoming bone marrow biopsy or ECP session if laboratory results show the level to be too low relative to a cutoff point. They learn that there are restrictions to eating, drinking, and taking medications prior to particular medical procedures. They know that a fever above a certain cutoff point means a trip to the emergency room in the after hours. If they are to get labs drawn locally (i.e. in their hometown instead of the health system in which the clinic is located) they learn how to get orders for these. They learn how to make arrangements for scripts to be sent to their pharmacy or how to use mail order pharmacy. Even the requirement to live in close proximity to the clinic in the first 100 days post-transplant is an important institutional requirement. All these and more are relevant knowledge as the patients and caregivers navigate the system in which patient care takes place.

It is usually the case that institutional scaffolding takes place during face-to-face or phone encounters with BMT clinicians. This type of knowledge develops over time as a patient and caregiver move through the transplant process and various needs arise that require relevant know-how. It is not quite feasible and likely would not be very effective to try to collect such information in printed format. However, while learning mostly takes place in context, it is possible to know that the need for certain information will arise at particular moments. Hence, underlying temporalities can inform organizational processes that could help structure institutional scaffolding. For instance, transitional periods are particularly intensive with regards to institutional scaffolding. Getting acclimated to the outpatient clinic structure, learning how to manage patient care when a patient gets to go home after day 100, and coordinating care between different providers as a patient transitions out of BMT are important temporal markers. Given the many difficulties all participants report with the transition out of BMT, it could be particularly beneficial to organize the institutional scaffolding concerning that process.

7.1.3. Scaffolding on Managing Social Interactions

A third area in which BMT patients and caregivers benefit from scaffolding is managing social interactions with others outside the clinical context. The nature of transplant is such that it profoundly influences when, how, and with whom one socializes, imposing significant restrictions at particular times and posing specific difficulties at others. While social interaction can be challenging in many different ways over the course of a transplant, there are definite patterns as to the timing of certain predicaments.

First, as expected, hospitalizations often constitute crisis situations or time blocks in which socializing with others is heavily managed. Both hospital guidelines and personal preferences dictate how socializing occurs in these periods. For instance, hospital guidelines generally limit the number of visitors in a patient's room to two at one time. Exceptions may be allowed, such as when Mrs. Isles had several people from her inner circle in her room on the day of her transplant. Even though there is not a formal policy in place, clinicians often recommend the patients and caregivers limiting visitations to immediate relatives and close friends, particularly at times when the patients' blood counts are low and the risk for infection is high. Mr. Martin's son noted this in a mass message to his parents' friends, since they had been asking about visiting Mr. Martin, telling them that the clinicians recommended visitors to be limited to family members until his father's immune system recovered from the chemotherapy. The patients and caregivers are also instructed to be particularly careful about having children as visitors, because there is risk for being exposed to various contagious diseases. Infrequent visits by children came up in support group meetings, where hospitalized patients and their caregivers noted the difficulty in not being able to see small children often during inpatient care. Besides limiting access to a patient in general, interactions with visitors are managed by asking them to follow certain precautions, such as trying to avoid kisses and hugs and making sure to wash hands upon entering and leaving a room each time. As described earlier under "Patient Experiences," social interactions are also limited by institutional means when a patient tests positive for an infectious agent. In such cases neither the patient nor the caregiver are permitted to enter common rooms (in fact, the

patient is in isolation), or to otherwise socialize with other patients, in order to prevent the spreading of an infection.

On the other hand, the patients themselves sometimes prefer not to have many visitors (barring their caregivers and perhaps select others) during hospitalizations. Besides the need for precautions, some patients I interviewed recalled not wanting to see people because they were feeling very sick. In these cases some of them used mass media to manage communications, while other patients relied on the select few who visited them to pass information on to others. For instance, Mrs. Isles, who normally had her husband and several friends share caregiving responsibilities for her, recalled how she did not want to talk to anyone except her two main caregivers at the time she was in the hospital with a serious infection:

“I had an infection. It was just really painful, and I was in and out of it. That’s when they had me on the morphine and everything else. [My friends] couldn’t, they didn’t get to come up and visit me. All the other times I was like, yeah, come on up and see me. That was the one time I just, I was out. You know, and um, and it was hard for them. It was the hardest for them because they couldn’t see me and then they knew where I was at. They knew the pain level I was at. And um, so I was just living it. So it was harder, I think at that time, it was harder on my caregivers. And it was only like two caregivers in that room, you know, it was [my husband] and [a friend] were here. And that was it. You know, at that time nobody else was here. And it was the first time I just, like, I didn’t want to talk to anybody cause all my energy was focused on just getting better or trying to not feel the pain.”

In the quote above, Mrs. Isles identifies her hospitalization as a particularly difficult time for her friends, who could not see her because she limited her interactions to focus on her recovery. She stated in her interview that her friends had their own support group among themselves, and would share news of her and their worries with one another. Essentially, the caregivers on the inside helped to limit and manage interactions with those on the outside. This kind of arrangement becomes more difficult when many people are eager to get news and to see the patient. Therefore, in order to help manage social interactions, the BMT unit recommends their patients set up personal CarePages, which can be accessed from the rooms on the ward. Mrs. Adams said she followed this recommendation and that this approach helped her immensely. She remembered feeling bad for not wanting to have

visitors, because she did not want to worry anyone or hurt anybody's feelings. At the same time, feeling as sick as she was, she felt the need to make a choice:

“That was good for, to tell your other relatives. Like whether or not it be me updating it. Most of the time when I was inpatient my husband updated it. Then as a patient I don't have like people calling or people bombarding him, texting him or texting my phone, like constant, you know. Cause being in here for the transplant was different than when I was in before, or even getting put back in remission. That was like a walk in the park, whereas this was way more intense. You know the chemo was really hard, I was really sick after, and you know the whole like, just getting up, showering, eating, or doing my walks everyday. That was it you know. I didn't have time to be on the phone talking to everybody... I mean, I know people feel, and it's hard, it's a hard thing, cause then it's hard for me as the patient because I feel bad because I don't want to see anybody. Because then it makes me feel bad cause I don't want to make them feel bad, does that make sense? But when you're really feeling like that, I mean, coming to see me isn't going to do you or me any good, you know.”

Mrs. Adams, quoted above, found CarePages to be helpful because it made it possible to update and communicate with everyone while limiting visitors to the hospital. Also, note that her husband was the one to post updates during her hospitalization. In the outpatient phase she eventually took over this task. She stated in her interview that using CarePages helped her husband, who had to manage communications on top of everything else. Her experience – shared by other patients and caregivers – underlines the delicacy of maintaining social relations while allowing patients and caregivers to focus on recovery. Mrs. Adams also remembered not allowing visitors who had been around sick children, noting that this is “a big no-no.” She said the BMT clinicians warned her not to have visitors with even the remote possibility of being sick, not even if they used a mask, and she had been adamant about following their recommendation.

In effect, for BMT patients and caregivers, hospitalizations are generally marked by isolation from others, especially from people outside the immediate family and perhaps a small circle of friends. The difference from many other illness contexts, including the patients' own experiences of illness prior to transplant, is that the isolation continues for much longer after the patients are discharged from the hospital. Due to high doses of immunosuppression, BMT clinicians instruct their patients to continue to follow infection precautions carefully. Among other things, these include monitoring visitors, avoiding crowded places, and being diligent with the use of masks and hand sanitizer. At the same

time, the patients cite feeling ill and the extreme fatigue as reasons for continuing to avoid socializing with others. As described earlier, they generally spend the first few months following hospital discharge at home (when they are not at the hospital for a visit or procedure), mostly sleeping or engaging in low-level activities. Their descriptions of life at home indicate having only their caregivers around them, with occasional visits from close family or friends. As the patients start to feel better they begin to do more, but most patients and caregivers report being “conscious” or “leery” of germs. The first few times they go out they generally keep it low key; going to a restaurant or grocery shopping with caregivers are examples participants commonly gave. Then they gradually reintegrate into social life. Mrs. Adams, who deliberately limited visitors because she wanted to focus on her recovery, started by having a couple of friends over to her house around two months post-transplant. She then started going to church. She recalled how she had to actively manage interactions with others:

“And we went to church a couple times, but sat like upstairs in the balcony and tried to get out as soon as, before people wanted to like hug me, you know. Like I remember the first time one of my aunts or someone came, and I’m like, you can’t, don’t, you can’t hug me. I just kind of got to, you know, or like people want to shake your hands, well, you know, nice to see you but I’m not gonna shake your hand. Sorry, just cause of germs and, you know, always had like the gallon thing, the sanitizer, in my purse.”

At this point in the transplant process, the challenge is to make others aware of how they should interact with someone who has had a transplant and is still at high risk for infections. The patients – like Mrs. Adams quoted above – have to actively inform others regarding what they could or should not do. Some of the patients and caregivers have a harder time with this. For instance, Mrs. Harris constantly worried about her husband being exposed to infections, but the couple was also wary of being too restrictive in their interactions:

“I was just worried the whole time. You know, and um, a lot of people knew he had been sick and, you know, had a transplant. *But they don’t know*, you know, anything about it. So they have no idea of what you have to be careful with and everything. They just don’t know. But I did, so I’m going aaah. You know, just worried. It was, it was really *hard*. But at the same time, uuuh, I mean you can’t put a cage around him, you know. So, but we try and tell them. They’ll say can we come over. Sure, just as long as you’re not sick. You know, when they ask. Um, but when you’re in places like church, you know. As long as you don’t have contact. Like, after we got home from church Sunday we both

went in and we both washed our hands really good, because people were shaking your hand and how are you doing and everything, and you don't want to go "don't touch me, don't touch me" (laughs), you know. I mean, you don't want to act like a, you know, like you're a pariah or something, and stay away from me. But, you know, we're aware of it so *we* do the precautions more than the people that are around us taking precautions." [Emphases original.]

Mrs. Harris' account again highlights the delicacy of maintaining social relationships while trying to manage illness on a daily basis. When the topic is raised, the BMT clinicians offer recommendations on how to begin reintegrating into social life, reinforcing basic precautions such as avoiding hugs, kisses, and handshakes, and suggesting ways to indicate to others that a patient is still not done with recovery. The following is an excerpt from Mr. Davis' clinic visit with his physician extender on day 100, which illustrates an example of social scaffolding at that time. Mr. Davis wanted to have more freedom in doing things. His wife, worried that he would get sick, preferred that he wait a little longer, even though the clinicians felt comfortable clearing him for some activities. At the visit, Mr. Davis and his physician extender discussed how he might use a mask to indicate to others that they should be careful around him:

The patient asked: "So this is day 100. What happens next? Am I more free to do things?" The extender said that, although lowered, the patient is still on Tacro and steroids; so he still needs to be careful. The extender added that after the immunosuppression is done he would be able to do more, although he can still do things now. For example, last time he had asked about going to church. The patient laughed when he was reminded of this, and responded by saying that his wife had prevented him from going last week. "What's another week?" the caregiver commented. The patient asked whether he should wear a mask. The extender said it depends: if he's kind of on the outside then it's possible not to wear it, but if he's more "in the middle of the action" then he should wear a mask. The extender then noted that the mask is more for other people to remember [that they should be careful around the patient] than for the patient himself. The patient nodded his agreement, but also added, "you don't want to have all the attention either."

At the clinic encounter described above, the extender re-confirmed that Mr. Davis could resume some activities, such as attending church. Note that Mr. Davis was not quite sure how he should manage interactions with others, and specifically asked about wearing a mask. He preferred not to get the kind of attention a mask would draw on him. Still, the extender's recommendation was to use one if he interacted with others at close proximity, particularly because the mask would serve as a reminder for others to be careful around the patient. This specific use of a mask – as a reminder – is also stated in the printed

material provided to patients prior to transplant. The general instruction in the printed material is for patients to wear a mask in crowded places to remind both others *and themselves* to be cautious. Otherwise the mask is not that preventative for catching infections. At an interview six months post-transplant, Mr. Davis told me that when he started going to church he at first purposely got there when the service was just starting or a couple minutes after, and left when they were getting ready to dismiss the service. This way he avoided conversing and “mingling” with a lot of people. He continued this for about three months before he started going a little earlier and staying a little longer, talking to others as long as he could see they were not sick.

Mr. Davis is among the patients who were able to make it to day 100 with few enough complications that it was possible for him to get cleared of certain restrictions at that time. For those patients who do not do as well – an estimated 40%, according to one extender – being able to socialize more is both risky and a much needed change. In these cases the clinicians continue to rely on personalized decision-making – as described in the previous chapter – recognizing the importance of providing some relief to both patients and caregivers. For instance, Mr. Perry had a particularly difficult time with acute GVHD and steroid-related issues in the first few months of his transplant. Past day 100, while he still had significant ongoing issues, his physician extender decided that there were benefits to socialization despite the risks:

The caregiver asked if the patient is now beyond the point where he could have visitors as long as they're not sick, and people without a flu shot since the flu season is over. “Cause we really haven't been doing that” [i.e. having friends/visitors over], said the caregiver. The extender said that the patient is still considerably immunosuppressed, although on lower dose steroids and Tacro than what he has been on so far [the patient commented at this point that he's probably feeling better today because he's on a lower dose of steroids]. However, the extender added that the patient should have visitors, noting that the benefits at this point outweigh the risks. Both the caregiver and the patient nodded in agreement.

Note that Mr. Perry's physician extender warned the couple about continuing infection risk, which is a standard response to all patients still on immunosuppressants. On the other hand, given that Mr. Perry had had a very tough time so far with the transplant, the extender made the call to give a little more freedom in having visitors in order to provide

a morale boost for the couple. The couple, quite aware of the risks as well, agreed that the benefits would be substantial. At a subsequent visit, Mr. Perry – like some of the other patients I interviewed or whose visits I observed – commented that different friends “babysit” him when his caregiver is out of the house.

Findings from this study suggest that there are clear temporal points in the transplant process at which it would be particularly beneficial to use social scaffolding to help patients and caregivers manage their social interactions. The first of these is the transplant hospitalization. As described above, at this time socialization with others is fairly restricted, in part due to clinician recommendations and in part because the patients are usually feeling quite sick. Social interactions are similarly restricted during re-hospitalizations following transplant, but it is likely that what is learned during the initial hospitalization will be carried over to subsequent hospitalizations. Still, it is possible that reminding patients and caregivers of the ways in which they might handle social interactions could help. A second temporal point where social scaffolding would be useful is when patients are approaching day 100, or when they are specifically cleared of certain restrictions that allow them more flexibility to socialize with others. This transition in the transplant process is particularly important from the perspective of social scaffolding, because it follows a long period of isolation for the patient. Finally, as described in an earlier chapter under “Patient Experiences,” several patients have noted that managing social interactions is in some ways more difficult when one begins to look “normal” on the outside but has ongoing chronic issues that affect daily life. At the time these kinds of challenges arise – usually farther out from transplant – BMT oversight tends to be less frequent and the patients are trying to adapt to the changes in their lives. Hence, it is a problem often associated with gradually transitioning into survivorship. It could be beneficial to employ more directed and explicit social scaffolding to help address these kinds of difficulties when patients are making this transition.

7.1.4. Emotional Scaffolding

Due to the aggressive nature of the treatment, the high risks it involves, and the intensity of the process itself, transplant places substantial emotional burden on both patients and caregivers. Whereas emotional responses may be triggered at any point during the course of a transplant, there are again discernible temporal patterns that could help to structure psychosocial assessments and support. In this section I provide a few examples of common emotional experiences to underline the importance of scaffolding via information-in-time in helping the patients and caregivers navigate through the process.

As discussed in the previous chapter, prior to transplant the patients and caregivers are in crisis mode and try to focus on immediate concerns such as attending to their families and practical matters (e.g. making funeral arrangements or taking leave from work). As expected, worry, fear, and grief are among the emotions that often supersede all others at this time. The possibility of death or an impaired quality of life loom large, with patients and caregivers noting that the information they receive is all “negative” and “scary.” Besides having to cope with their own emotions, they worry about the reactions of family members – particularly children – and that adds considerably to their distress. Some patients also suffer from significant physical pain from their disease, which increases their burden further. In Mrs. Allen’s case, she tried to cope with her own grief and anxiety as well as her adult children’s, while she was also in a lot of pain from her disease:

“I was never, um, scared? I felt terrible for my family. When you’re the mom you’re supposed to make everybody else better. And when you’re making everybody else sad, and then putting them out of their normal routine because of something you have, it’s uh, it’s the ultimate mother guilt (laughs). You know, they were, I was just, I *was not* prepared for how upset the girls would be. They were *extremely*, extremely upset over the whole thing. And that kind of surprised me (laughs). I don’t know why, but it did! [Interviewer: How did you deal with that?] Well, prior to transplant I was not feeling well, so I remember saying I can handle my grief, I can handle my anxieties, but I can’t handle everybody else’s. Um, so, how did I handle that? I just tried to be as normal as I could be. I was in a lot of pain. A lot of bone pain. And um, you know, tried to do as much for myself as I could. Um, I hovered a bit (laughs). So we just kind of got through the time. But I felt, you know, I tried to stay upbeat and everything. Like (laughs), I remember one time saying, I am not dead yet. So, let’s, let’s not act like I am.” [Emphases original.]

Amidst fear and anxiety, some patients and caregivers choose to avoid negative information to help them cope with their situation, while others prefer to know more in order to feel better prepared. In fact, there is a whole range of information preferences; from wanting to know as little as possible to wanting to know as much as possible, as well as being selective about information. Respecting people's information preferences, in large part to help them cope emotionally, while ensuring that they know enough to make informed decisions is a difficult part of clinician work. Consider Ms. Lauren's case. When she started to read the material provided to her prior to transplant, Ms. Lauren saw the devastating odds for survival. She quit reading the informational material altogether – which is a relatively common response – and turned to her physician for reassurance. The physician's approach was to support her by indicating that they would focus on any positive aspect that could help her achieve a favorable outcome:

“They gave me a notebook this thick when I, after I was diagnosed and this was right before, not long before I ended up in ICU²⁸. But, um, they gave me a big thick notebook with a lot of information about bone marrow transplant. And um, on the very first page as I was reading it, it uh, said that of people who are fifty five and older when they're first diagnosed with AML, and that's how old I was when I was first diagnosed, of those people less than 20% are still alive two years later. Last I, I'm not liking those odds! I mean that was just *devastating* to me. You know so I talked to, at the time hematology-oncologist was [names physician], so I talked to him and he says we have to look at what puts you in that 20%. Um, anyhow, I obviously beat those odds. Although came dangerously close to being part of that statistic because, you know, as I say, you know they told my family I had just hours to live. But, after that [information] was on the very first page of that notebook, I closed that notebook and said, I don't need to know that, I'm gonna just take one step at a time and face it as I do. So I never reviewed that.”

When asked how she tries to balance the need for sufficient information with responses to negative or scary information, Mrs. Taylor – a social worker – described an approach similar to the one Ms. Lauren's physician used. Mrs. Taylor explained that she has to assess the patients for their basic understanding of risks, but then she also points out anything positive that may be in a particular patient's favor. For instance, having a related donor (i.e. underlining lower risk of GVHD), having a great support system (i.e. underlining the importance of the caregiver), or living close to the hospital (i.e. underlining the importance of quick responses to issues, as well as comfort). This

²⁸ Intensive Care Unit.

approach, while meant to help the patients and caregivers cope with negative information and emotions, is also informative about transplant.

Other emotional difficulties are temporally specific to patients and caregivers as well. For example, as described in the previous section, the transplant hospitalization and the first few months of outpatient care are marked by isolation from others. Patients and caregivers generally associate these time blocks with the patients feeling very sick, having limited social interaction with others, and spending all of their time in clinical contexts or otherwise immersed in patient care. These time blocks also often involve separation from young children. The separation, combined with the fear of dying and leaving children and other family members, make these periods even more difficult to bear. For instance, at a support group meeting of hospitalized patients and their caregivers, a young mother noted that she was not ready to die because she has small children and they need her. The hospital context is also difficult for some people because they tend to make comparisons to other patients. For example, Mrs. Langdon – a caregiver – said that she was very scared for her husband when he was in the hospital for transplant, and felt like they were “in prison, because he couldn’t leave.” She worried that “he would not make it,” explaining that there were all these wives at the hospital and their husbands seemed like they weren’t making it. It is important for the patients and caregivers to recognize their emotions at these times and learn how to cope with these emotions. For instance, in Mrs. Langdon’s case, her worries were caused in part by hearing from other women how sick their husbands were. In similar situations as hers, where people make comparisons between patient cases, the BMT clinicians warn that comparisons are dangerous (emotionally) and futile, because each patient’s case is different. This is meant to help patients and caregivers learn not to make direct comparisons, and to provide them with a means to cope when patients around them are not doing well.

Findings from this study indicate that there can also be some delay in psychosocial responses associated with crisis situations – particularly hospitalizations – as well as serious complications and other periods of intense treatment. For example, after her

husband was re-hospitalized a number of times (which she noted as “downers”), Mrs. Martin noticed that she has “a pattern” in how hospitalizations affect her. She said that the stress does not surface until she lets her guard down in the aftermath, and she has “a good cry” that “holds [her] quite a while.” She stated, “When [my husband] and I are out of a crisis in his recovery, there is more time to think rather than just get through each day. That's when you have to face feelings head on.” Note that “crisis” was Mrs. Martin’s own choice of words, not informed by this study. I observed this delay effect in other patient cases as well, and it suggests that emotional scaffolding could be done in a more temporally targeted manner. In fact, the clinicians are aware that emotional responses can surface as after-effects and they address these at clinic visits if the topic somehow emerges. For example, at a clinic visit a little over two months post-transplant, Mrs. Adams’ physician extender was prompted to discuss emotional responses to transplant upon hearing from her and her caregiver that they had had an argument. The following is an excerpt from my field notes on that visit:

The patient and the caregiver off-handedly stated that they had had an argument. After completing the rest of the visit the extender decided to come back to this. The extender noted how the patient might begin to experience the emotional effects of what she’s been through, now that she’s actually feeling better. Patients around day 100, and also when they’re at six months, feel better physically, and that’s when the emotional stuff will really hit them, the extender explained. Up until then it will be all about ‘I can’t think about the emotional stuff because I need to go get chemo, and I’ll get the next chemo, and I’ll get the transplant, and then I need to take all of this medication,’ and then there comes the point where things settle down a bit and the emotional stuff really hits. “You’ve been through so much,” said the extender to the patient, “and you’ve been through so much too,” added the extender, looking over at the caregiver. “I think it’s really important to acknowledge that.” The patient agreed that she had had a very difficult time, citing a period right before her relapse as particularly stressful. She briefly described this period and how emotional it was for her. The extender again emphasized that it’s important for both of them to acknowledge what they’ve been through together. The caregiver nodded in agreement. The patient noted that they [i.e. the couple] have also been together 24/7 over the past few months, so that wasn’t helping probably.

In the excerpt above, note that the extender identified a temporal connection between illness experiences and having an emotional response. The extender explained that emotions tend to surface later, as a patient begins to feel better physically and both the patient and caregiver are able to process their emotions. This explanation prompted the patient to open up about a period that had been particularly difficult for her. Throughout the conversation, the extender made sure to acknowledge that both the patient and the

caregiver had been through a trying experience. The couple agreed, with the patient noting that having been together 24/7 for months was probably causing some strain as well. The discussion was therefore both informative, with regards to emotional responses, and allowed the patient and caregiver to reflect on their experiences and acknowledge their emotions. A point to note here is that the extender's temporal estimates for delayed emotional responses were largely based on disease time, as both day 100 and six months were mentioned as general timemarkers. However, Mrs. Adams was almost a month short of day 100 when this visit took place. Mrs. Taylor, who addresses emotional responses more often as a social worker, noted that she frequently gets calls to talk to patients before day 100 – usually around 60 to 90 days post-transplant. It is possible that patients and caregivers may benefit from emotional assessment and scaffolding, such as provided by Mrs. Adams' extender, within this temporal period in the transplant trajectory.

While emotional responses can surface when a patient begins to feel better physically, as described in the previous chapter responses can also surface when a patient feels sicker than how he expected to feel at a certain point in the transplant trajectory. I discuss this in more detail in the next section to illustrate a particular strategy for emotional scaffolding commonly employed by BMT clinicians. It is important to note that there are also exceptions to Mrs. Adams' observation that being together with one's caregiver 24/7 over a long period of time and through an extremely intense process can cause emotional strain. For instance, Mrs. Lewis recalled how she went through what she called “a little depression kind of a thing” when she got to go home after her day 100, which she attributed to the fact that as a patient she had grown used to having her husband with her all the time. She said that, when they went home, her husband started to attend to other chores and wasn't with her all the time anymore (Mr. Lewis said he was trying to catch up with tasks at home since they had been away for so long). So Mrs. Lewis took over some of her own care, such as flushing the triple lumen catheter and running her IVs. She said she felt better when she realized that her husband had to check in on her to see that she was okay. In her case, Mrs. Lewis' experience coincided with the transition around day 100, and the changes that came about with that transition. Note that she mentioned

not having her husband with her like she had gotten used to during a difficult time block in her illness trajectory (i.e. first 100 days), and taking over some tasks that her husband had taken responsibility for during that time. Her experience suggests a potential misalignment of temporal perspectives between patient and caregiver following the transition, where the patient has not yet adapted to the changes associated with the transition while the caregiver's priorities in the trajectory have shifted. I observed that, unless a patient's illness trajectory unfolds with major complications, caregivers gradually stop accompanying patients to clinic visits. The patients take more responsibility for their care instead. It is possible that different temporal perspectives between patients and caregivers in the time block beyond day 100 have psychosocial implications, in which case emotional scaffolding prior to the transition, and assessment following the transition, may be beneficial.

In the course of a transplant, complications that a patient or caregiver did not expect, dealing with prolonged ill health, and the ups and downs of a series of seemingly never-ending hurdles give rise to psychosocial responses. In this study, even the patients who had few complications were taken aback by the nature of some of the issues they had, such as a particularly troublesome bacterial infection commonly called *C. diff* that affects the intestines, which patients often described using a version of "something you wouldn't wish upon your enemy" or "worse than everything else combined." In cases where issues stacked up one after another, the patients and caregivers eventually began to feel worn down. Some of them commented that they never expected all the complications that emerged in the course of their transplant trajectory. Mrs. Scott – caregiver to her husband – said that they had been told the transplant was going to be "a long journey," but she had had no idea of the many complications her husband would end up having. Mr. Scott agreed that he had had "no clue of what [they would] be going through." Mrs. Martin also noted that they never could have imagined her husband having so many complications; each time they hoped the new "stumbling block" would be "the last downturn," but new challenges kept coming up. Among the biggest of these were the ups and downs of chronic GVHD, which Mrs. Martin described as "disheartening." More than a year out from transplant, when they felt in a particularly "dark place," Mrs. Martin recalled what

their oncologist's extender had told them while Mr. Martin was still going through chemotherapy: "You will have peaks and valleys, bumps in the road." When they hit a difficult time, the Martins tried to remind themselves of all the other times they had come across an obstacle – a "bump in the road" – and got through it. The description of the transplant process that the Martins' extender gave them helped the couple get through these difficult times. I have heard other patients and caregivers use words and phrases such as "hurdle," "obstacle," "roller coaster ride," and even "bump in the road" to describe their experiences. This is an interesting point with regards to the rhetoric used by the clinicians. Transplant is often described by clinicians as "a marathon" or "a long journey," which indicate the long-term and difficult nature of the process. On the other hand, these descriptions may suggest a more or less "straight path." It is possible that descriptions such as "peaks and valleys" provide a different conceptualization of illness, normalizing multiple complications and changing emotions as part of the process.

While many temporal experiences, including the ups and downs of illness, are common across patients' transplant trajectories, disease relapse is a crisis situation experienced by some patients, and one where emotional scaffolding is essential. A relapse situation is very difficult to navigate for patients and caregivers. The questions that come up at clinic visits where news of relapse is given generally pertain to how a patient and caregiver might break the news to loved ones, and what to do next. The BMT clinicians provide considerable advice and support at these visits to help individuals navigate these situations. Clinic observations are consistent with Mrs. Taylor's experiences as a social worker as well. When asked how one talks to a patient whose disease has relapsed, Mrs. Taylor explained that she first tries to listen and understand where the patient is with the news. She said the common response by patients is to ask how they are going to tell their kids or spouses. In these situations, what the patients and caregivers need to learn is how they might manage emotionally charged interactions. In this respect, it is possible to say that emotional and social scaffolding overlap, as the patients and caregivers must gain some strategies or skills for navigating social interactions with others given a particular situation (i.e. a dying patient). Due to the heavy patient load of the clinic, and therefore limited time of social workers, social workers do not get notified of all disease relapses

immediately; however, Mrs. Taylor stated that she will get called if the patient is alone, the news was unexpected, or the patient or caregiver is taking the news with great difficulty. In other cases, the BMT clinicians try to help a patient and caregiver in thinking through decisions.

Many patients who survive transplant live with a number of chronic issues acquired during the treatment process. As noted in an earlier chapter, in this study, common problems reported by patients who were a year or more out of transplant include fatigue, loss of stamina, and impaired short-term memory. Many of the patients also had issues with multiple forms of chronic GVHD, which in some cases were quite debilitating. Other long-term issues were psychosocial in nature: depression, feelings of loss, and changes in identity. In some cases, the patients' and caregivers' lives were altered significantly, with role reversals – such as who provides for the family – being common occurrences. Mrs. Taylor noted that, from a psychosocial perspective, the most difficult cases are those in which the patients and caregivers must learn to accept and adapt to their radically transformed lives, as in cases where the patients suffer from GVHD. These situations are challenging for patients and caregivers to navigate. One of the strategies used to help with this process is *normalization* (Sanderson et al., 2011), which I discuss in the next section.

7.2. Addressing Problems in BMT via Scaffolding

As discussed so far, timely information plays a crucial role in illness management from a number of perspectives. It can help to instill general awareness in patients and caregivers and empower them to actively participate in the care process, allow them to learn the institutional routines and processes that structure patient care, help them manage social interactions with others outside the clinical context, and support them in coping with the emotional effects of illness and treatment. In the next two sections I illustrate examples of scaffolding applied to particular problems in BMT patient care.

7.2.1. Managing Expectations

As described earlier, one of the biggest challenges in the BMT clinical context is the unawareness or uncertainty that patients and caregivers have at times with regards to what is “normal” at any given point in the transplant process. Comparisons between a patient’s current state of health and how it was prior to transplant, as well as the wish or hope to regain what is lost during treatment (i.e. the return to “normal life”) often fuel this problem further. Patients and caregivers also tend to have expectations regarding the trajectory of illness, which may be influenced by the basics of BMT clinicians’ trajectory schemes, the information provided to them in printed material, or comparison to other patient cases. Misalignments between their expectations and the reality of illness sometimes lead to temporal knots, as described in the previous chapter. In all these cases there is the need to realign their expectations or their general view of the illness trajectory with those of the clinicians for a more realistic assessment of overall health and progress. The BMT clinicians and social workers frequently engage in this kind of information work, and many of them refer to it as normalizing or normalization (e.g. Sanderson et al., 2011). Normalization can involve emotional scaffolding, disease/treatment scaffolding, and even scaffolding to help with social life.

Findings from this study indicate that the need for normalization arises more frequently in the first few months post-transplant (i.e. within the “acute” period), as well as much later in the transplant process as part of the transition to survivorship. Previously, I alluded to several common situations in which this strategy is used early in the post-transplant phase: in addressing the level of fatigue, nausea, loss of muscle mass, loss of taste, loss of appetite, re-hospitalizations, and the emotional responses that tend to emerge following intense periods of treatment. These are common complaints by patients that are addressed as normal occurrences by the BMT clinicians. Patients often raise these complaints multiple times during visits in the early post-transplant period leading to repeated reassurances by the clinicians that the issues are “normal,” “common,” “expected,” or “not at all unusual.” Over time there is either an improvement in the

particular issue reported or a patient accepts that the situation “is what it is,” as patients and clinicians sometimes say.

Other common situations in which normalization is used relate to the fear of disease relapse. The fear of relapse, while ever-present, is more pronounced in the first year of transplant (and even more-so in the first 100 days until the biopsy), since patients and caregivers are told that the risk decreases significantly after that time. However, there are circumstances that can misleadingly trigger this fear in the first few months post-transplant unless these are explained by the clinicians. The most common of these is fluctuating blood counts. As mentioned earlier, the patients and caregivers are extremely sensitive to fluctuations because it was through the counts that disease had revealed itself in the first place, and changes in the post-transplant phase might indicate that it is returning. Hence, changes cause agitation and prompt questions to clinicians regarding why these might be happening. At the same time, it is fairly common for the counts to fluctuate as the new marrow continues to recover. Furthermore, infections and some medications (such as Bactrim, which is used to prevent a certain kind of pneumonia, and Valcyte, an antiviral used for a fairly common infection) can significantly affect some blood counts. In several of the clinic visits I observed, the clinicians had to reassure the patients and caregivers that the changes in the counts were most likely caused by a reason other than disease relapse. Each time the clinicians noted that what they were seeing was normal at that point in the transplant process under the given conditions, and then stated that they – the clinicians – were not worried. The facial expressions and body language of the patients and caregivers suggest that hearing an explanation coupled with the disclosure that the clinicians are not worried tends to provide some amount of comfort.

Besides blood counts, imaging and procedure results also often have to be explained by the clinicians for purposes of reassurance. For instance, Mr. Perry had gotten a bone marrow biopsy and one of the tests done (flow cytometry) showed a little bit of disease present. Upon reviewing the results in the exam room his physician immediately informed the Perrys that this wasn't at all unusual at this point in the transplant. He noted that it would not have been good news if the disease were still around for the most part,

but that was not the case. He explained that the presence of a little bit of disease means that they'll "continue to be vigilant and continue to work at it." The physician then explained that in the first place they would taper the immunosuppression (to get some graft-versus-leukemia effect). He also noted that if there is still residual disease later on they could give Mr. Perry more of the donor cells. This way the current situation was normalized, and both an immediate plan and a plan for the future, if needed, were laid out. There are other situations in which a similar approach is taken by the clinicians; for example, in explaining changes in the percentage of cells of patient versus donor origin. These questions most often come up within the first few months post-transplant, and the information is provided immediately to normalize any seemingly out-of-place situation.

A third context in which normalization is used relates to medications. For example, one drug that the clinicians find themselves having to explain to patients and caregivers is an antipsychotic that is actually used for appetite and anti-nausea with BMT patients. When alternative medications do not address a patient's problem effectively in these respects, this medication is sometimes prescribed. In these cases the clinicians introduce the drug at clinic visits by specifically stating that they are not prescribing it for its antipsychotic property. For instance, Mr. Harris had been complaining about appetite loss and nausea at several clinic visits in a row, and he had tried several anti-nausea medications, none of which seemed to work. After suggesting a particular way in which he might try taking the anti-nausea medications he was currently on for another week (e.g. one medication before meals and another one after), Mr. Harris' physician extender noted that if this doesn't help then they could try one other medication. The extender explained that this other drug is actually an anti-psychotic, but studies have shown that when given to patients it increased appetite and helped with nausea. The extender stated that for this reason the drug is now used for these purposes as well, and reiterated that if prescribed for Mr. Harris it would be prescribed to help with appetite and nausea. In the clinic's teamroom after the visit, the extender explained to me the reason for bringing this up with the Harris' now: because "patients Google all their drugs all the time." The extender said that if they did they would immediately see that the medication is an antipsychotic and may become suspicious of why it's being prescribed. It turned out that Mr. Harris was indeed

prescribed the medication later. However, at the first visit following the prescription the caregiver raised the subject with the physician (she had indeed reviewed information on the drug), who essentially provided the same explanation as the extender did in the earlier visit. The same information was given to all other patients I observed who were prescribed the medication. Normalization is also used in talking about narcotics, as patients sometimes get addicted to these over time. Clinic observations show that when a patient shows signs of addiction or confides having difficulty “quitting the pain pills,” the clinicians make sure to emphasize that this problem is common; or as Dr. Matthews told one of his patients, “it says nothing about you.” The clinicians then try to get the patients to wean off the narcotics slowly.

Whereas normalization occurs routinely in the first few months post-transplant, as well as at other times as needed during the transplant process, the most salient use of it is associated with the common BMT rhetoric of eventually reaching “a new normal.” Despite patients’ wishes to return to their pre-transplant selves and lives as much as possible, BMT clinicians try to manage their expectations to this end. As chronic issues begin to stabilize the patients must accept – if they haven’t already done so – all the changes and adapt accordingly. Observations and interviews suggest that for patients and caregivers acceptance and adaptation are processes that evolve as a transplant trajectory unfolds. For example, a patient accepts and adapts to the extreme fatigue, the overall loss of stamina, each chronic manifestation, and so on, as these happen over the course of the transplant trajectory. However, a major difficulty arises farther out in the process for the patients with chronic issues that affect their quality of life. For example, at a clinic visit, Mrs. Lee described how sad it made her recently to have to drop a fitness class that she had been taking for a very long time. She said she looked around the class and saw everyone else being able to do the moves and she thought to herself, “everyone can do these and I’m the only one who can’t.” She added, “And that made me sad a little bit.” Fitness had always been important to her, Mrs. Lee explained, and she felt her GVHD and overall physical condition were affecting this aspect of her life. She said she could take a class for patients going through cancer treatment, adding that she would be the only one in the class her age, “but that’s okay”. Mrs. Lee’s physician responded by noting

that she is taking a healthy approach; that it is good to be aware of her limits but to continue to try new things and do her best. Hence, as patients begin to come to terms with the changes to their bodies and lives, the clinicians encourage them to accept and adapt to their “new normal.” Mrs. Taylor – the social worker – explained that helping patients with severe chronic issues was one of the most difficult aspects of her job, because the patients’ (and caregivers’) lives are changed significantly and they find it challenging to accept these changes. In these cases, she noted, there is very little left in the patients’ lives that resembles past identities and circumstances:

“And it’s really, it’s sometimes so limited. Literally sometimes I’m just talking with people about, we call it goal-directed activity. I’m like, even if it’s just a shower. That’s all you do for that day and it wipes you out, but *something*. *Something* that you have to complete each day. I don’t care what it is. And I try to find out with them, like, can it be something other than a medical appointment, you know. Because they, yeah it’s like they lose all their purpose. And their role... It’s another thing, like when I talk with families, like a lot of times I’ll say to a caregiver, your husband in this case let’s say, doesn’t seem like a husband anymore. He’s not providing for his family. He’s not really a dad to his daughter anymore; he can’t go to her sporting events, he can’t whatever. He’s just like a patient here and he’s your patient. He’s not your husband anymore, he’s not a father anymore, he’s not the grandfather anymore. You know, it’s like so much loss. I’m just talking with people about, you know, now it’s a new dynamic. Instead of looking at all the things you can’t do, and I’m more, what can you do? And it might look really like nothing. But we got to find something in there. You know. Well I can still talk with my daughter about her game. And I can still, you know, cook dinner for my wife before she comes home from work because she has to work now. Or I can, whatever it might be.”
[Emphases original.]

Even in not so extreme cases, the patients report constant battles with GVHD and problems with memory and stamina. From their jobs to their roles at home the patients experience so much loss that acceptance and adaptation become real work. At the same time, as chronic issues stabilize the majority of the patients transition from the care of BMT clinicians (except for their chronic GVHD issues) – who have come to know them and their particular situations extremely well – to care providers who know very little of them or the ordeal that they went through. It is imperative to help the patients and their caregivers as they work to adapt to the new normal. How to effectively manage this as they move into survivorship is a key question.

7.2.2. Managing Resistance

Many of the patients who participated in this study cited loss of independence as a very difficult aspect of transplant, depending on others physically and/or losing – at least temporarily – much of the freedom that was taken for granted prior to illness. Loss of independence in certain ways was very demoralizing, such as when Mr. Harris depended on his wife to put on his clothes and when Mrs. Isles viewed asking people for help as one of her major obstacles. However, even losing the freedom to do normal activities (e.g. gardening, driving, eating favorite foods) and to make decisions (e.g. personal schedule, where to live or travel) required adjustment. At times the patients were patiently accepting of their circumstances, assuming an attitude of “it is what it is” and hoping to experience positive improvements. There were times, however, when they pushed back on certain restrictions or aspects of treatment to maintain some sort of normalcy and control over their lives. Going against clinician recommendations, these types of pushbacks – or resistance – come across as one facet of non-compliance or uncooperative behavior. Identifying resistance is essential for implementing scaffolding to at least reach an agreement between all parties.

In some cases resistance occurs despite sufficient knowledge of the risks of the behavior involved. There is a kind of defiance, at times overtly and at others covertly put into action with respect to clinician awareness. Incidents of resistance are interesting in part because they provide an alternate viewpoint to patient-caregiver-clinician dynamics, and the role of information work when there are differences between the perspectives of the participants in patient care. For instance, in an interview a patient admitted to knowingly “breaking a rule” and how she managed this in the clinical context:

“I mean it was funny, cause like you know (laughs) the doctor told me at first that I wouldn’t be able to wear any makeup. I was like, (laughs) yeah! Um, that might be the one rule I’m breaking. Cause [my physician] told me I wouldn’t be able to wear it for a year. And I knew right then that was, that was going to be one rule I’m not [going to follow]. Like, sorry... I mean I followed it for like a month. Followed it for a month and then... [Interviewer: Did you make any adjustments, like to the way that –] I did. Like I mean at first, cause I was afraid I’d run into [my physician] [elsewhere in the hospital]... So I just used cover up first. Then I was like okay, I haven’t run into [my physician] and haven’t got yelled at for the cover up and it hasn’t done anything. Like my skin hasn’t...

So when I did go for my check-up, it was a month afterwards, I didn't wear anything. It was in my purse for after the appointment. So then I just, you know, started adding a little bit. Just experimenting, you know cause, you know if it affected my skin then I would have stopped, but no."

Although determined to wear makeup despite her physician's recommendations against it and knowing the risks involved, the patient quoted above stated that she was extremely cautious about adhering to all other restrictions and precautions; this one thing, the makeup, she was holding on to. Note that the patient actually worked at not getting "caught" by the physician and worried that she would be, which indicates a type of relationship where one party clearly holds a certain degree of authority over the other. However, because the clinicians did not notice what was going on (since rule-breaking occurred outside the clinic setting), there was never an opportunity for them to intervene. This kind of resistance is extremely difficult to address unless the behavior produces negative consequences – in which case there is already a setback in the treatment – or somehow comes to the attention of the clinicians. The patients usually become less resistant or more compliant if an unwanted situation is caused by the behavior. Examples of this are flare-ups of GVHD because the patients decided to tamper with their immunosuppression from dislike for taking medications (or their side effects), refusing to put on sunscreen because they don't like it, or traveling out of state and getting hospitalized with infections. Unless a negative consequence arises however, the primary means through which the clinicians may become aware of resistant behavior is caregiver involvement. Essentially, it is very common for caregivers to tell on the patients, relying on the authority of the clinicians to help with the situation – hence, triggering information work. In fact, Mrs. Davis – knowing that her husband has a propensity for not always following recommendations – once joked with their BMT physician while he was writing up patient instructions at the end of a visit that he should write, "You *should* do this. Do whatever's on here." [Emphasis original.]

This kind of caregiver-clinician partnership is actively cultivated from the early days of outpatient care. The clinicians often make a point of asking the caregivers their thoughts and their reports on how their patients are doing, stating that they know the caregivers will be more truthful or open with them even if the patients are inclined to hide

information or underreport problems. There are countless examples of this, such as caregivers reporting that the patients are not taking their medications, not wearing sunscreen, or that they are lying about eating or not smoking, or engaging in risky behavior that could expose them to infections. For example, while Mr. White was gone from the exam room for a few minutes, his physician extender asked his wife how he's been doing. Mrs. White took this opportunity to report issues that Mr. White likely would not have volunteered otherwise, stating her worries to the extender:

The patient was in the restroom when the extender talked to his caregiver about how he's been doing. The caregiver believes that the patient is not doing well at all. She reported that he is very skinny, not eating anything, and is depressed, throwing up in the mornings, coughing, using marijuana, and also not taking his medications sometimes... The patient came back to the exam room. First, the extender noted how skinny the patient looked and asked if he was eating, and the patient responded yes. The caregiver looked shocked and silently rolled her eyes. Then the patient said he is eating but not as much as he should, and that's why he is not gaining weight... Then the extender asked about the coughs. The patient said "sometimes," at which point the caregiver again rolled her eyes, and mouthed "all the time." The extender asked if he is doing anything in the dirt and the patient indicated he's doing nothing of the sort. The extender then asked if the patient is smoking. The patient said no. The extender asked if he's smoking anything other than cigarettes. Then the patient admitted that he smokes marijuana sometimes. He added that he does so to increase his appetite. The extender talked to the patient about marijuana having things in it that may cause infections and also how smoke can irritate the lungs... Before the visit was over, the extender asked the patient if he is depressed. After a brief pause the patient responded affirmatively. Would he consider an antidepressant? The patient paused for a minute to think, then said no... [The extender] did not push, but told [the patient] that he should consider [an antidepressant] seriously, adding that the drug they would give would take time to work; it would be a couple of weeks before they would see an effect.

In the excerpt above, note that the extender followed up on every issue the caregiver raised. Mrs. White continued to correct her husband's reports, which forced Mr. White to acknowledge ongoing issues. The extender strategically brought the conversation to a point where Mr. White's marijuana smoking could be addressed. Once he acknowledged that he was smoking, the extender explained why this is a risky activity in which to engage, especially given his persistent cough. Based on the caregiver's report and the patient's own demeanor throughout the visit, the extender raised the question of whether or not Mr. White was feeling depressed. Since his issues had been going on for some time, the possibility of using an anti-depressant was discussed. The extender left the

decision up to the patient, noting that if they did take that route it would be a few weeks before they would see any positive effects.

While resistance can occur in many different ways, one of the biggest challenges relates to patients wanting to quit their medications. All patients, without exception, at one time or another comment on the large number of medications prescribed for them. Some of them tamper with their medications without alerting the clinicians and suffer consequences for this, such as when Mr. Munro got skin GVHD when he did not take his Tacro as prescribed. Others openly raise the issue with their clinicians. A common question at clinic visits is whether there is any medication that could be eliminated from the medication list; “I would like to get off some of these meds” is among the most frequent requests (which sometimes sound like demands) that the BMT clinicians receive. Depending on how insistent a patient is, such a request can cause considerable alarm and prompt a clinician to explain why the patient should continue to take all the medications as prescribed. These are instances where detailed treatment scaffolding is essential. Consider the following excerpt from a clinic visit where Mrs. Hayes – more than a year out from transplant – told her clinicians that she would like to stop taking most of her medications. She was motivated by her belief that she was experiencing side effects from at least some of her medications, and did not need to take others. Since what she wanted to do is very dangerous, as she could easily acquire a life-threatening infection off the medications she wanted to stop, her request immediately prompted the extender, and later the physician, to explain why she needed to continue with her regimen:

The patient told the extender that she would like to get off most of her meds. “All those antibiotics and antifungals and everything,” she said. The extender responded, “unfortunately you’re still on [the immunosuppressant] and so you’re at risk for all these kinds of infections.” The patient said she has never had a fungal infection. Then the extender pointed out that she hasn’t had an infection because she’s been on these medications. “Oh, okay,” said the patient. The extender proceeded to explain a little further that these medications “are prophylactic,” that they are to prevent infections from happening since the patient’s immune system is suppressed. The antifungal, the extender noted, is to prevent mold infection, particularly bread mold. It prevents infections that normally would not affect people with normal immune systems, but people with suppressed immune systems are at risk for these. The patient said “okay.” ... The patient brought up the subject of cutting out some of her medications with the physician, briefly commenting that taking all the antibacterial medications is affecting her stomach. The

physician essentially repeated what the extender had said, reiterating that she is at risk for infections while on the immunosuppressant. The physician noted that the antifungal she is taking is to prevent bread mold, adding that even things that a regular person could fight off easily or would seem unaffected by, affect a transplant patient on immunosuppressive medication.

In the visit described above, the extender implicitly noted when Mrs. Hayes would be able to get off some of her medications: when she is off the immunosuppressant. Based on her response, this connection to the immunosuppressant was not something Mrs. Hayes knew about or understood. She did not know that the particular medications she had singled out were used as part of a prophylactic regimen, as she tried to make an argument for stopping the antifungal drug by noting that she had never had a fungal infection. The extender explained to her that she hadn't gotten an infection so far because the medications protect her. After this conversation Mrs. Hayes brought up the subject of medications during her visit with the physician, but this time she just stated that they are affecting her stomach. The physician (who had talked to the extender in the teamroom and heard about Mrs. Hayes' wish to stop the medications) reiterated what the extender had said earlier. Hence, the clinicians addressed the issue by providing consistent information and reinforcing the important points; taking the opportunity to teach the patient that preventative medications are necessary while still on immunosuppression. In the rest of this visit (not described above) the physician addressed a different issue that Mrs. Hayes was having that was likely exacerbated by one of her medications. Mrs. Hayes herself believed that the problem was caused by the medication and she wanted to reduce and eventually stop taking it. The physician agreed that stopping the medication would help with the issue and accepted this as part of the treatment for the ongoing problem. In the end a compromise was reached in terms of taking and stopping medications.

In Mrs. Hayes' case, mentioned above, the clinicians did not have a particularly difficult time convincing her of the importance of the prophylactic medications (and she also had a caregiver with her who was very engaged and involved in her treatment), although she was initially steadfast in her request. There are other instances where the patients are much more skeptical or fed up with certain aspects of treatment, and do not quite understand or accept the level of risk involved. In these cases the clinicians' job is much

harder, and they spend considerable time trying to convince their patients. Mr. Wagner, for instance, wanted to get off steroids, because he felt that the side effects he has been experiencing from the steroids is much worse than having GVHD. His insistence alarmed his physician due to risk of serious lung GVHD:

The physician asked how the patient has been doing. The patient replied that he's been doing okay. He's not been having shortness of breath, just a little cough. He complained, however, that the steroids were his main concern, indicating the desire to get off these as soon as possible. The physician noted that the concern is the lung GVHD, which is primarily why he has to be on steroids. The patient stated that he understands this, but the problems he's having from the steroids are worse than anything he's having with the GVHD... The physician, looking slightly uneasy, told the patient that the cough could also be from lung GVHD, and that lung GVHD is not to be taken lightly; of all GVHD, this is the one that people tend to die from, the one that tends to be the most serious. The patient said he understands this, but they aren't even sure that he has lung GVHD. He said they had arrived at this conclusion by a process of elimination [other causes for symptoms – declining pulmonary function tests, shortness of breath – were ruled out], so is the lung GVHD really there? The physician noted that that is the way GVHD is diagnosed, explaining that it is not even quite possible to diagnose it with a biopsy because the GVHD tends to be in different spots and it's not always possible to get it with the biopsy... The physician reiterated that lung GVHD in particular is very serious and it isn't really possible to reverse damages if they are caught late... [The patient said] that it's just frustrating to him because the side effects from the steroid are worse than anything he experiences with the breathing. The physician said that's understandable but they have to be careful with the taper, not go too fast. The conversation then turned to other means by which the side effects the patient was experiencing could be alleviated... At the end of the visit, the physician said they could taper the steroids a little bit, emphasizing that they wouldn't be doing a big taper, that they shouldn't. The patient has pulmonary function tests scheduled. The physician said they should wait for the results of those tests before talking about the next taper. If the results are stable or better they could go down on the steroids, but if the results are worse they might even have to go up on the steroids.

As described earlier, possibly the most difficult aspect of BMT is striking a balance between the prevention and treatment of GVHD and other complications that can significantly affect quality of life or pose life-threatening risks. The physicians carefully weigh the risks and often have to make tough choices; it is expected that oftentimes there will not be a course that completely satisfies a patient, because, unfortunately, one way or another the patient's health or wellbeing suffers. This was the case for Mr. Wagner. Understandably, he focused on the issues caused by steroid use that were noticeably and significantly affecting his quality of life. On the other hand, the physician was considering the alternative, worsening of lung GVHD, which clinicians know to be among the most dangerous complications. Essentially the discussion came about from

having to make a choice between current, debilitating issues and a potential life-threatening one. Complicating the matter was the fact that Mr. Wagner was not quite convinced that he had lung GVHD because of the way in which this type of GVHD is often diagnosed – through a process of elimination. The physician had to explain why the diagnosis is done that way and reiterated – several times – that this type of GVHD is not to be taken lightly as it is among the most deadly forms. At the end of the visit there was again a compromise made: the steroids would be tapered slightly, but not too much, until the next pulmonary function tests. The physician then noted that they could either go down or up on the steroids based on the results of those tests, indicating that there would be no compromise if the lungs seem to be worsening.

In the different cases presented in this section it is possible to see a variety of factors that influence resistance: wanting to hold on to some normalcy amidst the loss of freedom, suffering from depression due to the impacts of transplant on quality of life, being afraid of potential side effects from medications, actually experiencing debilitating side effects from medications, not knowing completely the reasoning behind treatments or diagnoses, and the difficulty in weighing current issues against potential future ones. Examples to each of these are numerous in the field. Essentially, for these and other reasons resistance is a complex phenomenon. A patient's experiences to date, both physical and emotional, can motivate certain actions. Sometimes the patients get away with a resistant behavior if they manage to carry on with it without getting "caught." Otherwise the clinicians often find out from the caregivers or become suspicious and begin to probe for answers. No matter which way they find out, the clinicians then have to explain or re-explain to patients why they should be compliant with treatments, restrictions, and precautions. Knowing the cause for resistance and providing information and support in a timely manner are key.

7.3. Scaffolding and Temporal Perspectives in BMT

In this chapter I described four different types of scaffolding that are essential for BMT patients and caregivers to navigate the transplant process effectively, and hopefully comfortably. Although I alluded to connections between scaffolding and temporality, in this section my goal is to highlight more explicitly the different types of scaffolding in relation to the temporal experiences and perspectives in BMT that were detailed in the previous chapter. I particularly focus on the viewpoint of patients and caregivers, since how they learn by scaffolding is of primary concern.

First, I consider scaffolding in crisis situations. As discussed in the previous chapter, being in a crisis makes it difficult for patients and caregivers to understand and process information, especially information pertaining to occurrences in the relatively distant future. They rather focus on coping with their immediate situation and attending to practical matters. This has implications for information work, particularly in circumstances where there is also considerable information overload, such as in the initial crisis that occurs prior to transplant. This crisis situation necessitates downstream scaffolding, especially with regards to diseases and treatments, since the patients and caregivers are able to learn and retain very little in these respects until the crisis somewhat settles and the information becomes more immediately relevant. Likewise, disease relapse – which is another crisis situation – involves a similar kind of information overload, in this case relating to understanding and choosing one of the remaining treatment or care options available to the patient. There is also a comparable complexity associated with the more immediate – and practical – concerns that patients and caregivers tend to have, such as giving loved ones the bad news. Therefore, in terms of disease and treatment-related scaffolding, it is important to consider and make available appropriate downstream processes to optimize patient and caregiver understanding, so that they can participate in the care process more effectively. At the same time, it is possible that there are certain crisis situations that do not necessitate downstream scaffolding to this extent. For instance, in a re-hospitalization in the post-transplant phase the “immediate” concerns of all parties (including patient, caregiver, and clinicians) may

be more closely aligned, with the overall focus being on what is going on with the patient medically at the moment. Hence, disease and treatment scaffolding can be more instantaneous in these cases. In all cases however, it is fair to assume that the patients and caregivers are likely mostly to retain information regarding immediate and practical concerns.

As discussed earlier, managing social interactions tends to be among such practical concerns during crisis situations. In BMT, the initial crisis and disease relapse present patients and caregivers with circumstances that require strategies or skills to effectively manage interactions with others. With the initial crisis, which extends into the transplant hospitalization, scaffolding for managing social interactions is also important because the patients and caregivers generally set precedent at this time for how they will manage interactions later in the process. For instance, they might set-up personal CarePages or delegate particular responsibilities to caregivers regarding communication with those on the outside. Then there is less need for scaffolding in subsequent crises unless a crisis presents a unique situation, such as disease relapse, where specific scaffolding can help the patient and caregiver navigate the situation.

Both clinic observations and interviews with BMT patients and caregivers suggest that in many cases there is a delay in psychosocial responses associated with crisis situations. Often, responses surface after a patient and caregiver come out of a crisis, when there is more time to think and process the experience. On a related note, psychosocial responses seem to emerge when patients begin to feel better physically after a crisis. This delay in responses has implications for the optimal timing for emotional scaffolding, in order to sensitize the patients and caregivers beforehand to potential psychosocial issues and to emphasize that such reactions are common and normal – thereby helping to manage expectations. Additionally, besides emotional scaffolding, a delay in responses suggests that timing matters in terms of when psychosocial assessments are made and interventions implemented during the transplant process.

While institutional scaffolding may seem to be important in certain situations of crisis, such as when a patient first comes to transplant and begins to get acclimated to the BMT context, or when a patient has to move to hospice care due to disease relapse, the scaffolding involved in these situations is generally related to transitional aspects that somewhat overlap with and follow from the crises. In fact, the need for institutional scaffolding is strongest during transitional periods, where patients and caregivers must get reoriented to the next time block. As noted earlier, transitioning to outpatient care, to the period beyond day 100 (or more generally, to the period with less clinical oversight), and to survivorship all require significant reorientation. In fact, this characteristic of transitional periods – the need for reorientation associated with significant change – make them particularly critical for all four types of scaffolding. For instance, different time blocks (separated by transitions) are often associated with particular risks for disease, such as acute or chronic complications, or late effects from transplant. It is essential that the patients and caregivers begin to learn the basics of what to watch for as a transition is made to a new time block, especially since they tend to focus on the immediate time block they are in or the one they are just entering. At the same time, transitions are often associated with changes to the patterns of social interaction or difficulties with social interaction, such as when a patient emerges, so to speak, from prolonged isolation following the first few months of transplant, or moves further into the chronic phase where it is challenging to explain to others that there are significant, ongoing health issues. Finally, as discussed earlier, psychosocial responses associated with significant changes tend to surface following transitions. Examples include declining caregiver involvement over time, and moving into survivorship with significant chronic issues. These types of responses could be anticipated and foreshadowed during the corresponding transition processes.

Finally, scaffolding in relation to temporal knots must be predominantly emotional, with a certain amount of information provided regarding disease or treatment in order to help realign the patients' and caregivers' expectations with the realities of illness. As described earlier in this chapter, managing expectations often involves such strategies as normalization to bring about an alignment. On the other hand, scaffolding after a

temporal knot has occurred and identified is a remedial approach. It is important to note that scaffolding can also be used to prevent the occurrence of such misalignments in the first place. This requires that the expectations of patients and caregivers be gauged, and the current state of care and health redefined along the transplant trajectory. Scaffolding can also be used for common situations, situations where misalignments are likely to occur, such as with post-transplant fatigue or discontinuation of immunosuppression.

In fact, a key point is that scaffolding can be used to prevent or address the kinds of informational issues that arise from various misalignments between different temporal perspectives, including those associated with the different perspectives of patients, caregivers, and clinicians. I already mentioned how downstream scaffolding, particularly with respect to diseases and treatments, is essential for addressing problems with patient and caregiver understanding that stem from the misalignment concerning the initial crisis situation. On the other hand, given the temporal misalignment between patient/caregiver and clinician perspectives associated with the transition around day 100, it would be particularly beneficial to provide disease and treatment-related scaffolding as a patient approaches this transition, since the possibility of chronic GVHD increases at this time and the patients and caregivers begin to assume more responsibility in watching for symptoms that could easily be attributed to other causes (e.g. shortness of breath to fatigue, or joint pain to becoming more active). Similarly, findings from this study indicate that disease-related scaffolding concerning potential late-effects from transplant would be beneficial for patients who are in large part transitioning from the care of their BMT teams. This would likely help to increase patient confidence with regards to one's own ability to identify potential transplant-related issues, and to better decide where to direct a particular problem – to BMT, a PCP, or a different specialist. Note that this also has to do with institutional scaffolding, since ideally a patient should be comfortable in making decisions regarding the necessary institutional processes to follow in order to get a particular issue addressed. At the same time, it is clear that a certain amount of emotional scaffolding is necessary to help patients make the transition to non-BMT physicians, since – as discussed in the previous chapter – the transition involves a significant psychosocial component. Finally, given that patients report difficulty with

effectively managing social interactions with ongoing – but potentially invisible – chronic issues, scaffolding for managing interactions could help to better prepare them for this new time block in the recovery process.

As seen in this site, scaffolding is – and could be – related to underlying temporal elements in the transplant process. A key issue is to pinpoint optimal timing for scaffolding itself, or information-in-time. Depending on where a patient or caregiver is at in terms of temporality, a particular combination of the different types of scaffolding can be used to benefit the illness experience. Hence, the temporal patterns in the experience of transplant can guide how scaffolding is organized effectively. However, there are also challenges to the practice of information-in-time from the perspective of clinicians. Among these one may include the sheer number of patients (and keeping track of or remembering what information was covered with each patient), the unique combination of issues that each patient has, the multitude of potentially relevant information to cover, limited clinician time, and varying levels of engagement and/or command by patients and caregivers. Organizing processes based on the underlying temporalities could help alleviate some of these challenges.

Chapter 8

Conclusion

Allogeneic bone marrow transplant is a complex, long-term process that unfolds over several months or years. Patients often struggle with various co-occurring complications, some of which are interlinked. The context is highly specialized, and novel to the patients and caregivers. Throughout the transplant process, the work that a patient, caregiver, and clinicians do for trajectory management are all closely intertwined; the trajectory is co-constructed via the interrelated efforts of all parties. This interdependence, the complex nature of the process, and the high risks it presents make it imperative for everyone to be on the same page, so to speak, regarding the transplant trajectory and the work involved in managing it. However, as the findings from this study reveal, there are differences in the ways in which participants in the co-construction of illness tend to envision and experience its trajectory. Specifically, there are differences in the ways in which time is experienced and the trajectory is anticipated, at times resulting in misalignments between temporal perspectives. Misalignments have implications for the organization of information work, specifically the type of information work between patients, caregivers, and BMT clinicians – scaffolding – that this study revealed to be collaborative and co-constructed by the participants. Findings indicate that scaffolding is essential for the patients and caregivers to develop the necessary knowledge and skills in order to navigate the transplant process and manage illness comfortably and effectively. As I note further below, both the type and timing of information are important to consider in the organization of this information work as the illness trajectory unfolds.

As detailed in this thesis, for the patients and caregivers at the field site for this study, the main temporal features associated with the transplant trajectory include crises, time blocks that are separated by transitions, and temporal knots where expected trajectories do not match the realities of illness. In each time block, there are often uninterrupted time sequences – periods of stability at the macro level, with ongoing situation management at the micro level. On the other hand, BMT clinicians use their professional knowledge of the temporalities associated with the diseases they treat, the treatments they use, the

human body, as well as their personalized assessments of where a patient is at with regards to illness, in envisioning and anticipating the potential illness trajectory of a patient. At the same time, it is important to note that none of these temporal perspectives – neither those of the patients and caregivers, nor the clinicians – are in reality truly exclusive to one group of participants, although they may be experienced and utilized to a greater extent by particular groups. In practice, all of these temporalities can be experienced in different ways by different participants under different circumstances, creating or modifying various misalignments with practical significance for the management of an illness trajectory and the organization of information work. As I pointed out in the literature review, the explication of these temporalities is a contribution to the literature. While this is the case for the BMT clinical context in this study, I do not believe it is theoretically limited to this particular context. These temporal abstractions are likely to be relevant in other illness situations as well, especially those that involve complex chronic illnesses, treatments that produce chronic conditions, and highly specialized medical domains. This study is the first one to detail the temporalities in a specific clinical context, discuss misalignments, and describe a means for preventing and addressing informational issues that arise from misalignments in terms of a particular kind of information work – scaffolding – and information-in-time.

In this study, I use scaffolding to refer to the collaborative information work through which BMT patients and caregivers acquire new knowledge and skills with the guidance of clinicians and other professionals, such as social workers. Over time, the patients and caregivers develop increasing competence within the BMT clinical context. At the same time, the patients and caregivers have their own expertise, information and knowledge, and they actively probe for information, and collaborate and negotiate with the clinicians in the learning process. Hence, as I show in this thesis, the information work itself is co-constructed, and is important for the patients, caregivers, and clinicians alike in the conceptualization and management of the illness trajectory.

The findings from this study indicate that there are at least four areas in which scaffolding is essential for the patients and caregivers to develop the familiarity and

expertise necessary to be able to manage illness effectively and comfortably. These include diseases and treatments, the institutional structures and processes in which patient care takes place, managing social interactions with others (particularly those outside the clinical context), and coping with psychosocial issues associated with illness and treatment. In this study I explicated for the first time how scaffolding in these areas are tied to underlying temporalities in the clinical context, which as I pointed out in the literature review and research questions chapters is an open question in the literature. Essentially, in order to be effective, this type of collaborative information work should be organized in the transplant process according to the relevant temporal experiences and perspectives. Depending on where a patient or caregiver is at in terms of temporality, a particular combination of the different types of scaffolding can be used to benefit the illness experience. The key is to provide, receive, process, and respond to information when it is practically germane.

Besides the main findings concerning misalignments between the temporal perspectives of participants in patient care, the collaborative nature of the information work involved and the organization of this work according to underlying temporal features, there are additional findings from this study that add to our knowledge from the existing literature. First, while there is consistency with the literature regarding the fact that patient and clinician perspectives of time differ, the data from this field site contradict the simplistic distinction dominating the literature that reduces the difference in perspectives to a view of “disease” (i.e. clinician perspective) versus “illness” (i.e. patient perspective). It is evident that BMT clinicians in this study do not envision a patient’s transplant trajectory solely with regards to how it may unfold based on “clock time” (i.e. to measure “disease state”). They carefully consider factors that relate to a patient’s illness experience, including being away from home and family, living under numerous restrictions and precautions, and dealing with both functional and psychosocial issues in daily life. These types of considerations run parallel to how a disease unfolds, but decisions are often made in a personalized manner. Moreover, while “disease time,” “treatment time,” and “body time” may in part be anticipated in terms of “clock time,” estimates or projections are never as easy or precise as what “clock time” may imply. A clinician does not simply

assess the risk for complications based on her or his knowledge of the underlying temporalities of disease, treatment, and the human body, but also on considerations such as the patient's or caregiver's attention to detail, perceived compliance, history of hospitalizations, personality, and an overall "feeling" for how the patient is doing, including the patient's and caregiver's own feelings vis-à-vis how the patient is doing. Hence, time as envisioned and enacted by BMT clinicians is a composite of multiple underlying temporalities. I also believe that this will generalize to other clinical contexts, especially with the advent of "personalized" and "patient-centered" care models in medicine. Consequently, any examination of temporalities in a clinical context must allow for the multiplicity and complexity that is likely to be present, including the many different perspectives of patients, caregivers, clinicians, and other parties involved in patient care.

Second, in this study, patient and caregiver experiences with transitions in the BMT clinical context suggest that these are important temporal periods in the transplant process for learning and re-orientation, and the meaning they assign to transitions may affect conceptualizations of the illness trajectory in ways that influence their own and the clinicians' experiences, illness work, and information work. For instance, associating a transition with getting better and having more freedom, whereas from the clinical standpoint there is still the need for caution, may result in the patients engaging in more risky behavior than what their medical situations warrant. To-date, the literature on transitions has largely focused on the experiences of and informational issues for clinicians, and continuity of care from the perspective of clinician work. This focus minimizes the roles and responsibilities of patients and caregivers – treating them more as passive recipients of care – and neglects their experiences. Findings from this study suggest that it is imperative to understand what transitions mean for them, and how they translate these meanings towards the work they do to manage illness going forward. Essentially, I believe that an important part of continuity of care involves the patient and caregiver being able to have continuity in their own work in the care process. This type of continuity has largely been neglected in the literature.

A critical transition for BMT patients is the eventual – and often gradual – transfer of clinical oversight to non-BMT clinicians, primarily hematology-oncology specialists and primary care physicians. As shown, this transition also involves misalignments between different temporal perspectives. At the field site for this study, many patients and caregivers feel that they need to get to a point – emotionally, as well as medically – where they feel ready to delegate aspects of their care to non-BMT clinicians. On the other hand, there is considerable variation in the ways in which the clinicians view and provision the transition. Some of the physicians follow specific criteria, such as initiating the transition around day 100, while others play it by ear depending on the particular medical situation of the patient. Hence, temporal misalignment between patient and clinician perspectives may occur in multiple ways – or not occur at all. However, in most of the cases I observed in this study, a misalignment was evident from the patients’ resistance to transitioning and the clinicians’ struggles to assure them that they are ready for it. Hence, the findings from this study strongly support the idea that there is a psychosocial component to the transition (Kantsiper, 2009), which is underexplored. Findings from the BMT clinical context suggest that this psychosocial component arises in part due to the nature of patient care in the early post-transplant period, which is closely related to the high risks of transplant, as well as the nature of the transition as a process itself. As noted, scaffolding – organized appropriately in time – can be used to alleviate this issue.

8.1. Study Limitations

As with any interpretivist work, the findings from this study are specific to the clinical context observed, and provide insight into the examined issues for the patients, caregivers, and clinicians of the study site. However, in interpretivist work it is possible to make cautious, theoretical generalizations (Strauss, 1993). I expect that differences in temporal experiences, and misalignments in temporal perspectives, will exist for patients and clinicians in other BMT contexts, with similar implications for information work. I also expect that different types of scaffolding via information-in-time will be important for BMT patients elsewhere in order for them to get to know enough to comfortably and

effectively manage their care. Although specific work practices – including how the transplant process is organized and managed – and some findings may differ among transplant centers, many of the issues identified in this study are likely to emerge in other settings given the nature and intensity of BMT. At the same time, as medicine becomes increasingly specialized, personalized, and involves complex processes, some findings similar to the ones identified in this study may emerge in different medical contexts. As noted in the previous section, I believe that the temporal abstractions that emerged from this study are likely to be present in other illness situations, and misalignments between these temporalities are likely to have practical implications.

For observations of clinic visits in this study, I primarily shadowed two physician teams. One of these teams specializes in chronic GVHD, and therefore focuses on patients who are at a later phase in the transplant process with specific kinds of chronic issues. I was informed, and personally observed, that there is considerable variation in how different teams operate and manage patient care in the transplant process. Although most of my visit observations are from my shadows of the two teams, I was able to observe other teams in the clinic's teamroom and occasionally shadow members of those teams in clinic visits. In my conversations with the clinicians in the teamroom, I probed for differences in style and team approaches to patient care in order to capture the present variation. Since I was able to talk to members of all teams, observe their teamroom activities, and occasionally observe their clinic visits with patients, I believe that the findings appropriately account for the variation with respect to the study's focus.

For the semi-structured interviews with patients and caregivers, I primarily recruited participants following their clinic visits, although a patient and two caregivers volunteered to participate after observations of support group meetings. Given the recruitment process, the majority of the patients and caregivers I formally interviewed work with the two teams I shadowed regularly. However, since the GVHD clinic receives patients from different BMT physician teams, and patients and caregivers from all teams attend support group meetings, I was able to formally or informally interview, or hear the experiences of, patients and caregivers across the different teams.

In order to examine the experiences of patients and caregivers with the two transitions I particularly focused on (namely, day 100 and the transition out of BMT), I had to use convenience sampling. For these transitions, I specifically asked to observe patient visits that matched the correct timeframe for the transitions – visits around day 100, and visits past six months post-transplant. However, I was able to capture and consider in detail the particulars of the cases I examined. This is standard in interpretivist research and a strength afforded by its methods.

In the data analysis for this study, the patients and caregivers are for the most part treated as one collective. In doing so, I paid attention to include only shared perspectives between the two groups, or otherwise highlighted relevant differences or unique experiences given the study's particular focus. However, it is likely that there are differences in the temporal experiences and perspectives of patients and caregivers as well, and there could well be misalignments with important implications. This is a consideration for future research.

8.2. Future Work

This study suggests a number of avenues for future research. First, in this work the focus has been on the experience of time primarily in relation to the illness trajectory, therefore time from a particular perspective and scale. The findings indicate that misalignments between the temporal perspectives of patients/caregivers and clinicians from this viewpoint, and at this scale, have implications for information work and the experience of illness. On the other hand, there are many other ways in which participants in patient care experience time at different scales, with potential for misalignments to occur (Klitzman, 2007). Future studies should look into the possible effects of misalignments at different temporal scales on information work, as participants try to manage the illness trajectory.

Second, as noted under “Study Limitations,” in this study the patients and caregivers were for the most part treated as a collective where findings indicated that their

perspectives matched. However, data from the field suggest that there are significant differences in the temporal experiences of these groups as well, particularly within specific time blocks. For instance, the time block following initial hospital discharge in the post-transplant phase is extremely busy and overwhelming for caregivers, who virtually have no time for themselves away from the patients. On the other hand, as the patients' conditions improve the caregivers gradually divert their attention elsewhere, while the patients are still immersed in illness routines. The patients in this study have noted that changes such as these have psychosocial effects, and effects on patient-caregiver relationships. Hence, it is likely that there are misalignments between patient and caregiver perspectives of time with important implications, such as implications for dyadic relationships, the experience of illness, and how these influence trajectory work. Future work should examine these issues.

Third, this study focused on the experiences and care of adult bone marrow transplant patients. As noted in the literature review, age is a mediator in the experience of chronic illness, particularly with regards to biographical disruption (e.g. Bury & Holme, 2002; Sanders et al., 2002; Pound et al., 1998). Hence, it is likely that children and young adults have different perspectives of time in illness compared to their caregivers (who are generally their parents) and clinicians. Understanding how temporality, as well as potential misalignments between different temporal perspectives, influences information work in the context of these age groups is an area for future research.

Finally, findings from this study show that scaffolding via information-in-time is essential in this BMT clinical context for the patients (and their caregivers) to gain the knowledge and skills necessary to manage their care and health effectively. Given the collaborative nature of scaffolding – rooted in social interaction – future studies should look into ways in which situated learning, in collaboration with clinicians, may be supported via processes or collaborative technologies to help the patients and caregivers in their illness work (Strauss et al., 1997).

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