

Information Work in Bone Marrow Transplant: Reducing Misalignment of Perspectives

Ayşe G. Büyüktür¹

School of Information¹, Department of Computer Science and Engineering²

University of Michigan, Ann Arbor, MI, USA

{abuyuktu, ackerm}@umich.edu

Mark S. Ackerman^{1,2}

ABSTRACT

Patients are often overwhelmed in their efforts to understand their illnesses and determine what actions to take. In this paper, we want to show why care is sometimes not co-managed well between clinicians and patients, and the necessary information is often not well coordinated. Through a 2.5-year field study of an adult bone marrow transplant (BMT) clinic, we show there are different experiences of temporal ordering, or temporalities, between clinicians and patients (and their caregivers). We also show that misalignments between these temporalities can seriously affect the articulation (coordination) and information work that must go on for people to co-manage their conditions with clinicians. As one example, information flows can be misaligned, as a result of differing temporalities, causing sometimes an overwhelming amount of information to be presented and sometimes a lack of properly contextualized information. We also argue that these misalignments in temporalities, important in medicine, are a general coordination problem.

Author Keywords

Articulation work; information work; chronic illness; collaboration; patient help; patient information; caregiving; temporality; temporal misalignment; information overload; health informatics; medical informatics.

ACM Classification Keywords

H.5.3 Group and Organization Interfaces, Computer Supported Cooperative Work

INTRODUCTION

People increasingly need help managing their illnesses in conjunction with clinicians and others. This is especially the case for chronic illness; it is often a difficult and frustrating experience. Patients get overwhelmed in their efforts to understand their illnesses, determine what actions

to take, and how to manage their conditions.

We wanted to examine why people often have so much difficulty understanding the information they are provided, and why they have so much trouble co-managing their illness with clinicians, in a 2.5-year study of a bone marrow transplant (BMT) clinic. BMT is a treatment used for blood cancers and disorders, as we will describe more fully below. It encompasses important aspects of chronic care and often leads to other chronic complications, as we will also describe more below.

What we found was that clinicians and patients had very different concerns based in their understanding of the necessary work. In this paper, we will examine how both clinicians and patients view the illness and their work. Many information problems in co-managing illness are caused by the differing perspectives of patients and clinicians, specifically in how they temporally experience their work within the unfolding trajectory of the illness. Patients need information based on their experiences of crises and transitions. As a consequence, patients sometimes do not understand information because clinicians and patients have misaligned information provision and information needs. However, the details of the BMT process, which we uncovered in our study, suggest potential technical ameliorations of this problem.

Based on our findings, we believe our contribution to CSCW is two-fold:

- As found in much of the prior literature, we show that the clinicians and patients can have fundamentally differing perspectives, which can lead to important misalignments in care, and more specifically, in information work. However, for BMT, the details of how the two perspectives differ matter for information overload, information under-load, and information misalignments. Understanding the details of how the two perspectives differ and unfold enables a better way to provide information to patients.
- As a practical consequence, we suggest design guidelines for collaborative information systems for patients and clinicians to tie information more closely to the experience of illness. This connection is often not well supported. We believe that ameliorating this

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disconnect can not only lead to better care but higher patient satisfaction.

To unpack these contributions, we first present some prior conceptual framings that we will use, show what has been done within CSCW concerning these questions, and then show what remains to be done.

RELATED LITERATURE

Background

In this paper, we draw on the pioneering work by Anselm Strauss and colleagues [1, 7, 30, 31] in which they used the concept of interactional (micro-level) *work* to study illness. In part, their studies focused on characterizing the different types of work done by clinicians [30] and chronically ill patients [7, 31] to manage illness. *Articulation work* is well-known in CSCW [13, 28], as it is the collective effort of participants (clinicians, patients, and so on) to bring together tasks and lines of work into working configurations.

Corbin and Strauss [7] discussed other types of micro-level work as well, such as biographical work (creating one's preferred identity, also used for example in Charmaz [4] to note the work that people did as their illnesses progressed) and everyday life work (such as housekeeping or marital work that must go on through illness). For Strauss and colleagues, *information work* is pervasive in all activities pertaining to different types of work (including articulation work). Information work was succinctly defined by Corbin and Strauss [6] as "the quest for, the receiving of, and the passing of information." This can include locating, gathering, sorting, interpreting, assimilating, giving, and sharing information [14], as well as the translation of provided information into the specific social context of an individual [17].

To discuss temporal orderings of the work, we use another concept from Strauss and colleagues [7, 8, 12]: *illness trajectory*. In their definition, 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 term includes the immense variety of events that occur as patients and clinicians try to cope with and control illness. We will use *illness trajectory* and *transplant trajectory* synonymously as both include the underlying diseases and treatments. We do this to make our descriptions clearer in places.

Reddy et al. [27] noted that the illness trajectory "creates a structured 'timeline' of activities, events, and occurrences...." Illness trajectories are then, by definition, arranged in time. But in a deeper sense, they are arranged within and by people's *temporalities* – the participants' sense and experience of time and their temporal organization of activities [27, 32].

Clinician-Patient Communication and Information Work

There is a very large literature on clinician-patient communication. There is a substantial literature on doctor-patient communication, which has been primarily centered in face-to-face communication. Our effort is to examine the possibility of technically-mediated augmentation for a part of clinician-patient communication, namely information work. Below we will cover the CSCW literature investigating requirements for supporting information needs.

Patients and clinicians have radically different perceptions of illness [9] and of time in relation to illness [3, 10, 24]. Specifically, by focusing on aspects of disease (such as its stages), the medical world tends to deemphasize the patient's lived experience of illness. Similarly, there can be sharp differences in the conceptualization of an illness trajectory between patients and clinicians [2, 20, 21]. For example, Becker and Kaufman [2] 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 views of recovery from stroke and of rehabilitation. While physicians viewed rehabilitation as the only option for 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. Despite an awareness of differences, support for clinician-patient information work is limited.

CSCW has tackled information work and care. Most of the work on medical care has focused on information work by clinicians, but some are highly relevant for how different groups coordinate and reconcile information work. For example, Munkvold and Ellingsen [25] noted that as the illness trajectory of a patient unfolds, common information spaces (such as care plans created for patients) are created as part of parallel information work, developed according to multiple disciplinary trajectories (e.g. physicians and nurses), with brief intersection points where the clinicians coordinate their activities. Their findings showed that common information spaces are situated, temporal, and regularly re-negotiated. Paul and Reddy [26], in their study of emergency care, found that clinicians often make sense of information collaboratively over time. The sensemaking trajectory of a situation 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. Our work also examines the often parallel and occasionally conflicting information work done over time, but adds patients and caregivers as essential roles.

Another focus of CSCW has been supporting patients in

chronic illness. Chen [5] argued for the need to support the temporal arrangement of chronic care cycles – the repeated clinic/homecare cycles by which patients receive, synthesize, and use information – in maintaining their illness trajectories. Klasjna et al. [19] noted that patients also have to deal with health information in “unanchored” settings where they “lack the informational, physical, and attentional resources needed to effectively engage in required information activities” (p. 193). They showed that factors that cause unanchored information work – including diminished attention, lack of familiarity with disease/treatment, the need for mobility, and inadequate work environments – affect patients’ abilities to accurately understand the information provided to them by clinicians. Mamykina et al. [22] showed how providing information to counteract a lack of information could support reflective thinking and could help diabetic patients feel more in control of their disease and personal goals. Building on this earlier work, Jacobs et al. [15] found that using a mobile and customizable tool supported by the patients’ healthcare system can help patients feel more prepared and confident. We note that [15] and [19] were with cancer patients, an area with known information overload [29]. In this study, we extend the prior CSCW literature about care and information work by focusing on the causes of information overload and under-load in care; we focus on how information handling is affected by perspective differences as they play out over time. Our work has a similar intention for support as all work in the CSCW literature, but unlike some earlier work with an occasional emphasis on the patient as acquiescent to a healthcare system (e.g. [16]), this work emphasizes clinician-patient information transfers as a source of partnership and collaboration in care.

FIELD SITE AND METHODOLOGY

The work presented here is based on a 2.5-year ethnographic field study at an outpatient clinic for adult bone marrow transplant patients in a tertiary research hospital in the American Midwest. The first author conducted over 700 hours of non-participant observation at the BMT clinic. This included observations of clinic visits by patients both pre-transplant and post-transplant, observations in the clinic’s teamroom where clinician teams worked, and observations shadowing three BMT physicians’ clinic teams (consisting of physician assistants and clinic nurses who worked with the physicians). Shadowing provided the opportunity to observe patient cases as they unfolded. Overall, we were able to observe more than 60 unique patient cases, including multiple visits by 27 patients over time.

The first author also conducted informal interviews with a variety of clinical staff, including 6 BMT physicians, 8 physician extenders (physician assistants and nurse practitioners who work in teams with BMT physicians), 5 clinic nurses, 6 transplant coordinators, a clinical research coordinator, and 3 social workers. As well, we conducted detailed semi-structured interviews with 16 patients (8

female, 8 male), and 9 caregivers (5 female, 4 male), regarding their transplant experiences. Patient and caregiver interviews focused on how informational, contextual (including temporal elements), and psychosocial issues affected patient and caregiver experiences during the transplant process. Each interview lasted one to two hours. In addition, we were granted explicit permission by one caregiver and the patient to use the blog the caregiver kept of the patient’s transplant journey for over three and a half years. We did an in-depth analysis of the 397 entries.

All field observations and informal interviews were documented with 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 and later transcribed. All but two of the interviewees (a patient and a caregiver) agreed to be audiotaped during their formal semi-structured interviews. We took detailed handwritten notes during the interviews that were not audiotaped and transcribed the ones that were recorded.

We analyzed our data using grounded theory methods [11] in an iterative process. Open coding was used particularly in the first few months of fieldwork to identify emerging concepts and themes from the field. We wrote analytical memos to gain more insight into emerging themes, and considered links between themes via axial coding. Once we identified core themes of interest with discussions between the two authors, data collection became more targeted. Selective coding was then used in the data analysis. We iteratively checked emerging understandings against the data, particularly against the presence of any negative cases. We verified the concepts and themes that emerged from this process through subsequent field observations and interviews.

This study was approved by our Institutional Review Board. In the following text, all names and details have been anonymized. Some quotes have been edited for clarity.

Next, we describe the bone marrow transplant process and what we found.

CLINICAL CONTEXT

BMT is an extremely complex process. In this section, we provide a simplified rendition to make our findings clear.

BMT is commonly used for the treatment of blood cancers and disorders. The type of transplant that we studied involves replacing the patient’s blood-producing stem cells in the bone marrow with those of a donor. This is done by first destroying the patient’s own stem cells using high dose chemotherapy, and then infusing the donor’s cells – much like a blood transfusion. The transplant does not involve surgery. Transplant involves many potential complications, particularly in the lengthy post-transplant period. Due to the many potentially life-threatening issues that may arise, transplant clinicians closely monitor their patients for at least one year post-transplant, often longer.

BMT trajectory. The BMT process moves along an often-standard trajectory, but the details of that trajectory are not known in advance. Before the transplant the patient's disease must be put into remission via chemotherapy, otherwise transplant cannot be done. As well, in order for the patient to proceed with a transplant s/he must have at least two caregivers (one primary and one backup) who formally commit to the process. This commitment involves, among numerous responsibilities, accompanying the patient 24/7 in the first 100 days following transplant – often the most critical period in the process.

Then, as mentioned, the patient's stem cells are destroyed through a special regimen of chemotherapy (sometimes along with radiation therapy) followed by the transplant itself. Once the new stem cells begin to grow and produce blood cells, the patient is discharged from the hospital if there are no complications. Because the first 100 days post-transplant are deemed critical from the viewpoint of complications that can quickly get out of hand, at this site, the patient is not allowed to live farther than a pre-specified distance from the hospital, where the outpatient BMT clinic is also located. This means re-location for many patients and the caregivers that are required to stay with them. At this stage, the patient is seen at the BMT clinic at regular intervals, at first commonly twice a week. As the patient approaches the so-called "day 100" milepost (which may not be exactly 100 days), if no major complications exist, the requirement to live close to the hospital is removed. However, the patient continues to come for clinic visits, at first once a week, and then at longer intervals. At the same time, many of the restrictions and precautions put in place after the transplant are relaxed or removed as the patient progresses beyond day 100. For instance, the patient may begin to drive, and eat some food items that were previously restricted.

BMT cases tend to be very complicated and challenging to clinicians and patients alike. Even though the transplant per se is not surgical, the physical and psychosocial effects on the patient can be severe. After all, one's ability to produce blood cells (which include cells of the immune system) is destroyed and then re-established using a donor's stem cells. In effect, the patient's immune system is replaced with that of the donor. The process is so often difficult and challenging that, as noted, a caregiver is required, and the challenges on the caregiver can be so severe that a caregiving contract must be signed for the transplant to proceed.

Graft-vs-host and other clinical complications. Many different clinical complications can occur. The major complication we will discuss in this paper is known as graft-versus-host disease (GVHD), which results from the donor's immune cells recognizing the patient's body as foreign and attacking it. GVHD can affect multiple organ systems simultaneously (e.g. skin, gut, lungs, and so on). Acute forms of GVHD, which are often described to be

“quick and angry” by BMT clinicians, usually occur within the first 100 days post-transplant. Chronic forms, which are described by clinicians to be more “stealthy,” tend to emerge later and last longer, sometimes for the patient's lifetime. Acute GVHD usually occurs in particular organs, whereas chronic GVHD can occur pretty much anywhere in the body (some forms being more common than others). Where and how severe GVHD occurs differs from patient to patient, but its effects can be extremely debilitating, even fatal. Since the disease results from the donor's immune cells attacking the patient's body, the standard prevention and treatment for GVHD is drugs that suppress the immune system, at times in very high doses. Once the patient's immune system is suppressed, there is a high risk for infections as long as the patient is on the medications. Patients are typically on high dose immunosuppression in the first 100 days. Balancing the risk of GVHD with that of various infections is complicated.

Since a BMT patient is often on 20+ medications at a time, side effects from these and any co-morbidities that the patient has must be continuously managed as well. For example, steroids used to treat GVHD can have multiple serious side effects (especially when used long-term), including osteoporosis, high blood sugar, mood swings and high blood pressure. Moreover, some medications (most notably ones that suppress the immune system) must be tapered off (i.e. decreased) gradually over time to avoid serious complications.

Hence, the BMT process involves potential complications with many diseases (e.g. GVHD, or infections of various sorts), and the need to prevent and treat each of these complications. Considering the complications that may arise, patients and caregivers are often faced with the daunting task of managing a complex illness trajectory in conjunction with their clinicians. The information work involved can be overwhelming.

Clinical environment. At this outpatient BMT clinic, patients remain under the care of the same physician throughout the transplant process. In the pre-transplant period, they work with the physician, a transplant coordinator who helps with the donor process and patient education, and a social worker. In the post-transplant period, the patients are under the care of their physician's clinic team, which consists of physician extenders (i.e., physician assistants or nurse practitioners) and a clinic nurse.

The BMT clinic was an excellent field site for our study. In BMT, close partnerships are required between patients, caregivers and clinicians. It is sufficiently complex and information-rich to examine information work and co-management in detail. Finally, the site allowed us excellent access, with the opportunity to follow and compare patient cases over time as their illness trajectories unfolded.

FINDINGS

In this section, we first describe how the viewpoints of BMT clinicians, patients and caregivers differ in relation to the management of transplant trajectories. Since our findings indicate that patients and caregivers often form a dyad, we have grouped the two in our description; in this paper we only talk about perspectives that are common between these participants. Below, after explicating the perspectives of clinicians and then those of patients and caregivers, we turn to the problem of misalignments with specific examples.

Clinician Perspective

Clinicians are most influenced by a medicalized viewpoint, that is, the diseases being treated and the various interventions (i.e. primarily treatments) involved in the transplant process. As well, they are also influenced by each patient's bodily responses to illness and interventions. Based on their knowledge and prior experience with these, clinicians are able to envision and anticipate the temporal trajectory of a transplant. However, in practice this framework is actively adjusted for each patient according to personalized considerations that are highly subjective in nature. Therefore, *diseases, treatments, the human body, and personalized considerations* most significantly affect how BMT clinicians expect a transplant trajectory to unfold and how they experience and manage the trajectory. We describe these in turn.

Consider Ms. Lauren's situation: She had an acute form of leukemia, which is known to be an aggressive disease that requires immediate intervention in the form of chemotherapy and transplant. Knowing the nature of the disease, her physician anticipated what must take place next and the timeframe in which the necessary steps needed to be taken. As in this example, from a clinical perspective, a transplant trajectory is primarily driven by the nature of the disease(s) a patient suffers. The diseases that must be addressed during the transplant process – the original disease, as well as others that arise post-transplant – all have particular temporalities. As mentioned, acute GVHD usually emerges within the first 100 days post-transplant, and chronic GVHD tends to emerge later. Everything from a viral infection to fungal pneumonia that may emerge as complications have anticipated temporalities associated with them. The clinicians' knowledge and prior experience with these set in motion a certain sequence of interventions based on established medical standards and protocols.

Like the diseases for which they are implemented, the various interventions used in the transplant process all have their own pace and rhythm as well. For instance, anti-rejection medication is started a few days prior to transplant so that it is in effect when the new stem cells are given to the patient. In the post-transplant period, the tapering down of medications follows standards of practice with regards to schedule. The dose of the main immunosuppressant medication, for example, is reduced every two to four

weeks. In another example, it takes time for each medication to show an effect, which can range from seconds or minutes (e.g. an inhaler) to weeks (e.g. an antidepressant).

In addition, bodily responses to diseases and treatments differ from individual to individual, but have their own temporalities as well. How soon a patient's body recovers from chemotherapy, how long it takes for the new stem cells to engraft (i.e. begin to grow and produce new blood cells), and a body's adjustment to or from various medications are all examples. To illustrate more clearly, one example that comes up frequently in the post-transplant period relates to steroid tapers (i.e., increase or decrease in dose). 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 of the medication. 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 readjust to making a sufficient amount of steroids on its own. The clinicians then instruct the patient on how to adjust the taper (i.e. dose and timing of steroids) if needed. A key consideration for BMT clinicians is to learn each patient's responses to treatments. This is an important part of getting to know patients, and the knowledge factors into the management of an individual's transplant.

Finally, the clinicians have knowledge of their patients and the caregivers at a personal level, and they use this knowledge to continuously adjust the activities and events associated with the transplant in a situated manner. For instance, the trust that the clinicians have in a patient or caregiver regarding how well they manage patient care influences the decision-making about clinical oversight. We observed several cases where the patients were allowed to decrease the frequency of clinic visits because the clinicians trusted that the patients or caregivers would call to report any emerging symptoms in a timely manner. Particular life circumstances, such as the financial 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 only two months out of transplant was cleared to be left home alone by the caregiver a few hours at a time to accommodate the caregiver's other obligations (despite the standard 24/7 requirement in the first 100 days), as long as the patient had "lots of back-up to call" if needed and "stuck to watching baseball" (i.e. did nothing dangerous). Dr. Matthews, a BMT physician, explained that decision-making in patient care is often highly subjective in nature:

It's intensely subjective. In deciding when to let them go home, for example, I consider several things. What's [the patient and caregiver's] attention to detail? Have they been compliant? How far is their home? Because a few hours out of town is very different from other side of the state. Has the patient been [re]hospitalized after transplant? And, you know, an overall feeling, my sense of how the patient is doing in general. Many things – it's very subjective.

We note that, in addition to their knowledge of their patients and caregivers, the personal styles and preferences of clinicians also influence their decision-making. For instance, some physicians are less strict about certain restrictions, such as when their patients might start driving their cars again or when they might begin taking short trips out of town. Although there is practice variation among the BMT physicians at this site with respect to specific considerations, all of the clinicians reported or were observed making personalized decisions for their patients.

Summary of the clinician perspective and how they anticipate the illness trajectory: The clinician perspective is that a patient's illness trajectory is discovered gradually, in a dynamic process, where prior knowledge and experiences with the temporal nature of the diseases that are present and the treatments that are used, observations of the patient's body, and subjective considerations about the patient allow the clinicians to anticipate and adjust the trajectory. In managing a patient's transplant trajectory, BMT clinicians work to favorably align the various temporalities for the various interventions (medical or psychosocial) to be effective. There are countless such alignments made in the course of transplant. Managing the antibiotic schedule to prevent or treat infections, adjusting the steroid taper to allow the body to "catch up," and allowing the patient to resume public activities based on the level of immunosuppression are just a few examples. Hence, the anticipated trajectory of illness guides the temporal ordering of care and associated information work.

Patient and Caregiver Perspectives

While the diseases, treatments, and bodily responses naturally affect BMT patients' and their caregivers' experiences of transplant, their perspectives are markedly different from the clinicians in significant ways, and these differences have important implications for patients' information work. For our participants, patients and caregivers experience and envision transplant trajectories instead as a series of *steady states*, *crises* and *transitions*. Diagnosis of a life-threatening disease, the prospect of undergoing transplant with many unknowns, a series of post-transplant re-hospitalizations, and disease relapse constitute multiple crisis situations. At the same time, the trajectory unfolds through a number of transitions, for example pre-transplant to transplant hospitalization, or a period of close clinical oversight to what is experienced as a period of increased freedom. While there are also relatively uninterrupted blocks of time in which the patient's

condition largely remains in steady state, patients and caregivers view their experience largely through the lens of crises and transitions. We describe all three in turn.

Crises

Crises have distinct characteristics. They are times of extreme difficulty where the illness trajectory takes a particular turn and important decisions must be made. Crises are emotionally charged, and there is heightened attention to the current situation. There is a sense of urgency. For patients and caregivers in particular, there is too much going on at the same time; too many unknowns and too many changes. Most significantly, crises force patients' and caregivers' focus to center on the present [4]. The demands of the present preclude thoughts about the largely unknown future, except for futures that are potentially lost.

Consider the experience of Mr. Roberts, a patient. When Mr. Roberts first heard his diagnosis of leukemia his reaction was disbelief: "Me? Cancer? Come on! You gotta be kidding me." He was on a road trip when the family doctor called, having reviewed his recent blood test, to tell him to turn around and go to the emergency room immediately. Chemotherapy started almost right away. As the treatment got underway, for a while all Mr. Roberts could think about was his profoundly altered circumstances with which he tried to come to terms. The early days were particularly emotional – he blamed himself for falling ill and thought about the past with regret. He thought about wanting to see his young child grow up, go to college, and get to be an independent person. He said he agonized over how they would break the news to his child. In his interview, he recalled being overwhelmed and noted that there was too much going on at the time. Besides treatment decisions, he had to work out various issues, such as making living arrangements in the vicinity of the hospital for the first few months of transplant. All of our patients recalled similar experiences and thoughts from the time they received their original diagnoses.

Caregivers also described similar experiences. Mr. Perkins, for instance, recalled his son's first hospitalization when a blood test at the local doctor's office sent him to the emergency room. Thinking back to this hospitalization, Mr. Perkins noted how the urgency of the situation prevented them from "moving forward" until further investigation could be done:

...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. ...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: [expletive]. [It was] as well my wife's mental reaction.

In his interview, Mr. Perkins remembered a sleepless night, followed by a flurry of activities over the next few days (such as arranging time off from work and attending to his son's immediate needs) until they were able to settle into a routine for the long hospitalization.

Disease relapse (i.e. recurrence) triggers a similar crisis situation, though our participants who have experienced a relapse described it as even more trying and disappointing than the first time they received the diagnosis. When Mr. Martin first got cancer it was treated only with chemotherapy, but disease relapse led to the decision to get a transplant. At the time of his first hospitalization after the relapse, when the search for a transplant donor was also initiated, his wife (the caregiver) described this crisis experience, particularly the focus on present circumstances:

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, the Martins were still trying to come to terms with the fact that Mr. Martin's disease had returned. 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. Five days after the transplant, Mrs. Martin noted that they were now able to look more into the future:

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. ...By the biopsy on day 100, a hundred percent of the blood cells should be from his new immune system. ...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. 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 what the couple perceived as the next stage for them in the treatment process.

Many crises, such as re-hospitalizations and disease relapse, can occur at different times in the transplant trajectories of patients. For instance, disease relapse can still occur after a transplant; there is no guarantee that the treatment will work. Crisis situations other than initial disease diagnosis and moving into transplant (which, as described, are in many cases temporally closely intertwined) exhibit the same characteristics of radically altered circumstances, difficulty, urgency, heightened emotions, being full of unknowns, and a distinct emphasis on the present. For patients and caregivers, it is often not possible to fully anticipate a crisis situation. On the other hand, transitional

periods in the transplant trajectory prove to be less unforeseen.

Transitions

Unlike crisis situations, in the many transitions that occur as transplant trajectories unfold (e.g. transition from transplant hospitalization to outpatient care, or from close clinical oversight to less oversight around day 100), BMT patients' and caregivers' perspectives are concerned with the future rather than the present. Transitions are generally characterized by changes that require reorientation on the part of patients and caregivers. Transitions involve modifications to established routines, including breaking out of or adjusting old ones, and making new ones. There is considerable uncertainty, but the nature of uncertainty is different from the kind 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, patients know that, if things go well, there will be some changes around day 100 that will enable them to have more freedom to do things. However, they are not quite certain what the changes will be and how these will occur. Similarly, caregivers expect to assume certain responsibilities once the patients are discharged from the hospital after transplant, but what exactly these include and the logistics of it all are not clear at first. There is much learning that takes place. For example, Mrs. Collins described the transition from the transplant hospitalization as getting "acclimated back to being home:"

Probably the hardest for me was just getting [the patient] acclimated back to being home, cause he'd been in the hospital for a month. And then I was 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 than anything.

All caregivers reported similar experiences as Mrs. Collins, noting that they had to acquire knowledge and skills that were in most cases entirely new to them coming into transplant. The patients, as well, had to adapt to new routines, both at home and at the BMT clinic. Hence, transitions are distinctly information-intensive periods.

Steady States

For patients and caregivers, crises and transitions punctuate discernable time blocks in which the patients' conditions are viewed to be in more or less steady state. In Mrs. Martin's (a caregiver) words, her husband's illness trajectory unfolded through the crises and transitions that separated these periods:

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 [Midwest City] which has lasted almost six months...This fifth block will be the recovery...returning home and living with chronic graft-versus-host disease.

In the quote above, we see Mrs. Martin identifying distinct periods of the transplant trajectory as punctuated by crisis situations and transitions. Each time block has its distinguishing feature (e.g. receiving chemotherapy treatment or being in remission). As with Mrs. Martin, we found that it is common for patients and caregivers to talk about their transplant experiences using significant markers that separate distinctive periods of time. These periods or “time blocks” are generally characterized by daily management of the illness trajectory and by “watch and wait” for changes to occur.

In summary, the patient and caregiver perspective of their transplant trajectory is one of experiencing a series of crises and transitions, with blocks of time in-between in which the patient’s condition is viewed to be in relatively steady state.

We found that in order to cope with and manage illness, our patients and caregivers want to have an overall idea of what to expect as the transplant trajectory unfolds. Oftentimes they form a simplified, idealized conceptualization of the expected trajectory that is largely based on their BMT clinicians’ early descriptions of the transplant process and information in the printed material provided to them. For example, questions directed at clinicians at pre-transplant visits commonly pertained to the overall transplant schedule: what chemotherapy the patient would get and when, what day the transplant would be on, the expected duration of hospitalization, general time markers in the post transplant period, and so on. The patients and caregivers also received a rough timeline of significant events, such as when acute or chronic GVHD might occur, when the patients might drive again, when they might work again, when they might be off immunosuppression, and so on. Patients and caregivers used all of this information to anticipate the trajectory of illness. To them, their conceptualization forms the basis of a “normal” transplant course, which they then use to assess deviations from the normal. However, the way they view how the transplant trajectory is likely to unfold generally represents a much-simplified version of the “best-case scenario” for BMT clinicians. We found that the patients and caregivers then had difficulty when their expectations did not match that of the clinicians. In the next section, we walk through two examples to illustrate misalignments between perspectives.

Misalignments Between Perspectives

So far we have described how BMT clinicians differ from patients and caregivers in their perspectives of the transplant trajectory. These differences also influence both how information is provisioned and needed.

In our site, information work is temporally ordered along the transplant trajectory - but in different ways. Clinicians tend to present enormous amounts of information at the beginning of the process, if only for informed consent. Patients and caregivers, on the other hand, are often overwhelmed by the sheer amount of that information, not having ways to incorporate the basic information and any contingencies either intellectually or emotionally. Information overload, especially at the beginning of the transplant process, is a significant problem noted universally by the patients and caregivers in this study.

Later in the BMT process, especially during crises but also during transitions, patients and caregivers often feel as though they are missing necessary information. Clinicians provide details on demand (and were very good about it in our site), but patients often feel that they are missing important details. Hence, information under-load becomes more of a problem as the transplant process unfolds.

Significantly, in this site, information provided by clinicians during crises and transitions is almost entirely oral. This makes personalization and customization easier, but makes it difficult for patients or caregivers to refer back easily. Remembering is often difficult, especially for emotionally-laden information, but also because patients and caregivers often feel physically exhausted – patients due to treatment effects, and caregivers from the arduous demands of caregiving.

Furthermore, as just noted, information is often very emotional. This occurs quite commonly at the beginning of the BMT process, but continues throughout. For example, Ms. Lauren (a patient) reported:

They gave me a notebook this thick after I was diagnosed and this was right before, not long before I ended up in ICU. 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 said that of people who are 55 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. I’m not liking those odds! That was just devastating to me.

Below we present two cases. The first demonstrates information overload at the beginning of the BMT process, when patients and caregivers are presented with too much information, much of which is emotionally sensitive. The second case shows the lack of information many people feel later during transitions. This can be information about the lived experience that is about to happen or the specifics of upcoming changes. Interestingly, during crises later in the BMT process, patients and caregivers can feel both a sense of information overload and under-load simultaneously. As mentioned, the information is often presented orally and is emotional, triggering information overload, and can be missing important details about their lived experience, triggering a sense of lacking information.

Case 1. Initial Crisis and Information Overload

As described above, for patients and caregivers crises are times of extreme difficulty marked by a sense of urgency and emotional turmoil. 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. For the patients and caregivers in this study, it is challenging to absorb and process information provided to them in the midst of a crisis. It is even more difficult to do so when the information concerns events in the relatively distant future. Hence, Ms. Lauren (a BMT patient) could not prioritize or retain information concerning GVHD when her physician provided this information in the preparation stage for her transplant. Rather, at the time, Ms. Lauren was trying to come to terms with her radically altered circumstances and attend to immediate matters such as arranging a place to live close to the clinic and finding a caregiver. In the following excerpt, Ms. Lauren describes how it was difficult to absorb the information and retain any details. Instead, she decided to worry about things as they came up:

I remember [the BMT physician] talked about side effects, of graft-versus-host disease, but it was overwhelming. 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. ...I needed a caregiver with me 24/7. I'm like, what? How am I going to do this? ...I live almost two hours away. ...So 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). I'll cross that bridge when I get to it.

On the other hand, while Ms. Lauren chose to focus on the information that had the most immediate practical value for her (such as finding a caregiver), her physician had a different view. He was thinking forward in time: Given the aggressive nature of Ms. Lauren's particular disease, a transplant would have to happen soon, and the physician was putting the next steps into motion, including providing detailed information for informed consent and education.

Other patients and caregivers overwhelmingly related strikingly similar experiences. For instance, Mr. Perkins, a caregiver who diligently researched everything from healthcare facilities to the particulars of research protocols and treatments as his son's transplant trajectory unfolded, noted that when his son was first admitted to the hospital his own goal had been to attend to immediate needs rather than to the details of the information provided to them regarding downstream events:

I think it was: go home, bring him what he needs. ...Um, and, just try to figure out how we're going to manage with this. 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. ...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.

While the patients and caregivers get stuck in the present (so to speak) in these crisis situations, the clinicians look forward into the trajectory to optimize the timing of transplant – and all the work that must be done to get to that point – in order to ensure the best outcome for the patients. Hence, the clinicians' present activities are oriented towards the future while the patients and caregivers are barely able to cope with their current circumstances.

BMT clinicians in our site acknowledged the problem of information overload and recognize that patients and caregivers are unable to retain much of the information, but they are not always aware that the information gets filtered based on the nature of immediate crisis situation. For instance, one of the clinic staff noted that members of the inpatient team on the hospital ward sometimes express surprise that the patients and caregivers do not know information that the clinicians know are provided to them before they enter the hospital. For patients and caregivers, information will need to be repeated, re-explained, reinforced, and provided with optimal timing for learning further down the process for them to actually understand what they must do to co-manage the transplant trajectory effectively. Providing information in a situated manner as the transplant trajectory unfolds is therefore critical – what we call the need for information-in-time. In our site, the clinicians did not do this consistently.

Case 2. Missing Information and Patient Expectation

We found that the patient perspective of the unfolding transplant trajectory around the so-called "day 100" transition often does not match that of clinicians, resulting in a seeming lack of information for patients and caregivers. This results from the misalignment between the clinicians' viewpoint of where the patients are in their trajectories and where the patients believe they are. This mismatch can cause significant clinical issues, even a downstream crisis, for the patient. For such situations to be prevented, information should be effectively presented to reorient the patients to the meaning of the transitions they are experiencing.

The BMT clinicians assess the significance of day 100 for a patient's transplant trajectory based on the temporal perspectives most pertinent from their viewpoint: primarily, risk for disease relapse, risk for acute and chronic GVHD, immunosuppressive treatment, and the patient's personal circumstances. For instance, Dr. Matthews described why he does not consider day 100 to be a major milestone:

Disease relapse, the risk is way high in the first one hundred days, for sure. Acute GVHD, the risk is way high first one hundred days. Perhaps from that perspective it's possible to view day 100 as a milestone. It's a milestone, but it's not a major milestone. The patient is not out of the woods yet.

As seen from this comment, the physician assesses the significance of day 100 predominantly from the perspective

of the treatment and the body's reaction to it. In fact, all of the BMT clinicians we talked to have the same perspective. While acknowledging that this time marker has some meaning from the viewpoint of disease risk, the clinicians unanimously labeled it as rather “arbitrary.” Although the risks decrease, a patient’s disease may still relapse, and even acute GVHD may still occur beyond this point. Moreover, since the tapering down of the primary immunosuppressive medication is begun around day 100 (an aspect of the treatment), there is the considerable likelihood that chronic GVHD will emerge. As Ms. Bailey (a clinic nurse) noted, “it’s not like the patients suddenly get better on day 100.”

In stark contrast to the clinician perspective, patients and caregivers put a lot of weight on day 100, even on the actual day itself. For instance, when Mr. White (a patient) was eighty-two days out of transplant he noted at his clinic visit, “Eighteen days and counting.” Mr. Bryant (a patient) joked with his clinicians that he would like a cake from them on day 100. The reason why patients put so much emphasis on the time marker is that they associate it with gaining more freedom from certain post-transplant restrictions and precautions – and thus associate it with getting better. Many patients get to move back home. They come for clinic visits less frequently, and begin driving after not being allowed to do so for many months. They begin to eat some foods they were not allowed to have, and do activities that were significantly restricted. Moreover, the patients get a day 100 bone marrow biopsy to check their disease status, and a disease-free biopsy offers further reassurance. Hence, from the perspective of most patients and caregivers the period around day 100 is unmistakably transitional, with what they see as multiple positive changes taking place for them.

This misalignment between clinician and patient perspectives is a significant one, particularly in terms of co-managing the transplant trajectory. Whereas the patients and caregivers associate the transition with the patient getting better, the clinicians worry about the increased risk of chronic GVHD. Since the patients get to move back home and come for clinic visits less frequently, more of the responsibility falls to them to look for any symptoms that may develop. They have to be diligent, since chronic GVHD is rather “stealthy” as the clinicians tend to describe it. There are also other risks. Infections and other complications may arise as well, and any changes must be noted immediately. Hence, associating the transition with getting better can unfavorably affect the transplant trajectory. Ms. Jones (a physician extender) said that patients and caregivers tend to delay reporting symptoms, believing that waiting until the next clinic visit would not make much of a difference. To the contrary, complications can get out of control quickly and sometimes are irreversible. Therefore, it is imperative to organize the information work to prevent adverse situations that could arise from patient and caregiver negligence. While BMT clinicians often provide information to alert the patients and caregivers that recovery is still a long road, this is generally

done in an ad-hoc rather than structured manner. Furthermore, relatively little information is provided about what will happen in their lived experience, e.g. what patients' "new normal" might be and its effects on daily life.

In summary, misalignments between the clinician and patient/caregiver perspectives can cause significant problems in information work, leading to potential issues for the co-managed care. In the next section, we discuss how our findings extend current understandings in CSCW.

DISCUSSION

In this paper we described how the patient and caregiver perspective of the transplant trajectory is markedly different from that of clinicians.

As was seen in the findings, the clinician perspective is predominantly formed based on biomedical models – prior experiences with the temporal nature of diseases and treatments, observations of the character of the patient’s body, and subjective considerations of the patient and caregiver. Clinicians understand that the transplant trajectory will unfold. It will do so in a dynamic fashion, and clinicians expect the trajectory will be discovered gradually. The dynamics are dependent on the diseases that will emerge, the treatments that will become necessary, the ways in which the patient’s body will respond, and the many personal decisions that will have to be made, all of which are often difficult to predict. There is constant change, and the changes are very complex due to the inherently complex interactions among the diseases, treatments, body reactions, and personal characteristics.

How clinicians experience the transplant process guides how they organize not only their management of care but also what they think should occur with patient information work. We found that because they see the transplant trajectory as dynamic and situated, they believe that patients must be provided information in a highly situated manner. Unfortunately all too often this translates into orally presented information, often based in biomedical models, prompted by and narrowly responding to patients' or caregivers' questions.

The patients' and caregivers' perspective, on the other hand, is one of experiencing a series of crises and transitions, with blocks of time in-between in which the patient’s condition is viewed to be in a relatively steady state. Crises are often frantic periods of intense information work combined with great emotional work, full of uncertainty and anxiety. Crises are about the *now*, too often along with fear for the future. Transitions are easier, because they bring the hope of progress, but they also bring uncertainty about what will change.

Patients and caregivers, with a few exceptions, cannot enter the social world of medicine [17]. They do not fully (or often enough, even partially) understand biomedical models. While they must understand how to look for GVHD, infections, or other complications, as well as how

to avoid those complications, they most often understand their situations through their lived experience – what they can eat or when they can garden (both being restricted due to risk of infection), how bodies will change, how shared activities will be curtailed, and what emotional issues will be raised. The attempted transfer of biomedical models, all too prevalent in this site, given en masse at the beginning of the transplant process, is overwhelming and results in information overload. Patients and caregivers, because they experience their transplant experience episodically need information when it is appropriate and as a result can also suffer from information under-load during critical periods.

Hence, the different perspectives on the transplant trajectory, and the resulting information work, come into tension, especially during crises and transitions. In our findings, we presented two cases where misalignments in the perspectives mattered.

Breakdowns in information work affect more than satisfaction. Since people must co-manage their illness with clinicians, having a common-enough understanding of the illness trajectory is necessary for maintaining care activities [30]. The shared understanding will never be perfect ([1] and [17]), but it has to be good enough for care activities to proceed.

We note that neither one perspective nor the other is correct per se. In their original description of the concept of illness trajectory, Strauss et al. [30] noted that individuals have their own concerns that profoundly affect their actions as an illness trajectory unfolds. And, as in Mol's [23] study that detailed how one disease is many other things at the same time to different actors, all of these perspectives are true; however, the differences must be reconciled to some extent (or held in abeyance) when they come into tension in order for the care and the information work to be accomplished well.

Reconciling or ameliorating these differences in perspectives is likely to be difficult, but needs to be done. As mentioned, a patient or caregiver will almost never know as much as a clinician about the medical issues [17]. Patients and caregivers will not have the requisite knowledge and experience to enter fully into the medical world [18], and clinicians will not have the requisite knowledge and experience to enter fully into the patient's lived experience. For example, patients might not understand why new medications are required and what their likely side effects might be. In turn, clinicians rarely, if ever, have the knowledge that comes with the lived experience of transplant, and may not know what the effects might be on a person's domestic or psychological lived experience.

This information work, nonetheless, could be made easier for patients and caregivers. CSCW as a field can help with this, as it has a long history of considering different perspectives in information work in design. Our findings

showed several important information needs and user requirements that we believe could be relatively easily satisfied:

- ❑ The amount of information presented at one time at the beginning of the BMT process is overwhelming. The key for patients and caregivers is to present the necessary information in a gradual but detailed manner to reduce information overload. At its most basic, this could be done via a collaborative software tool that can be populated from a library of information modules prepared by clinical staff. Modules should cover basic information about specific aspects of care (e.g. how to recognize specific symptoms of GVHD, how to give patients infusions at home). Given that each patient goes through transplant differently, it would also be useful to provide the capability for customization. Concomitantly, a suitable tool could also be adjusted to individuals' "informational styles" and cognitive capabilities.
- ❑ For patients and caregivers, re-finding information is an important source of difficulty during crises and transitions alike. Information should be presented in a way that can be revisited. Tools that make re-finding easier would likely reduce feelings of information under-load.
- ❑ Clinicians should be provided with mechanisms so that patients can signal their current information difficulties and the information they require; for instance, in understanding new medications or dealing with nausea that might lead to apparent adherence problems. Asynchronous mechanisms, despite the potential workload and workflow problems, should be examined.
- ❑ While clinician-authored data is valuable, the information should be restructured. Currently it presents biomedical models of the diseases, treatment, and side effects. This is important, but information should be structured around the lived experience of patients and caregivers. Patients and caregivers could best use information structured around their likely lived experiences. Information should be structured according to steady states, transitions, and likely crises. (Again, for patients and caregivers, it would be beneficial to present additional details as situations warrant).
- ❑ Finally, in our site, almost no information about the lived experience of BMT is given to patients or caregivers. While support groups are offered on the ward, most patients are too ill to attend them regularly. Patients in outpatient care rarely come to these support groups (although they are welcome) because they are already spending too much time in the hospital for their care. Videos of survivors and their families discussing their lived experience of transplant and conditions could manifestly help. Former patients and caregivers,

in addition to creating content, could help structure those videos.

While we have necessarily limited ourselves to BMT in this study, we believe that such an information tool could be useful across a range of chronic illnesses, especially ones that change relatively rapidly. One of the reasons we studied BMT is that it mimics many chronic conditions and medical treatments but with an accelerated schedule.

Our study has several limitations. First, this paper focused on two broad groups of participants: clinicians, and patients and caregivers analytically grouped together. However, our data shows that perspectives between patients and caregivers can sometimes differ. We have also found that hematologists and primary care physicians who eventually take over patient care from BMT clinicians (a transition we have not discussed in this paper) have different perspectives than the BMT clinicians. However, the issues caused by temporal misalignments carry and can be even more complex.

Second, our study was set in a particular medical context. As well, as with any interpretivist work, the particular findings (e.g. the different ways in which patients and clinicians experience time) are specific to the site and the clinical context observed. However, we believe our findings more generally hold, since in interpretivist work it is possible to make cautious theoretical generalizations [30].

CONCLUSION

In this paper, we described how the BMT patients and caregivers at our field site experience time fundamentally differently from the BMT clinicians as transplant trajectories unfold. We showed that time, as experienced and anticipated, affects the temporal ordering of information work along the transplant trajectory, resulting in multiple interpretations of the trajectory by patients and clinicians. Using two examples of misalignment, we illustrated that breakdowns occur in articulation work when patients and clinicians temporally order information work and co-managed care in incompatible ways along the trajectory. This kind of breakdown in coordination adds to the challenges the patients and caregivers have in co-managing illness in effective partnerships with the clinicians. The patients and caregivers either feel overwhelmed by too much information at certain periods of time or they do not have the information they need at the right time.

Hence, our study suggests that problems in coordination occur in part because of how different actors temporally order information work along the trajectory of collaboration, and that this differential ordering occurs because of how the different actors fundamentally experience time and conceptualize the trajectory of work.

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