# Transition and Reflection in the Use of Health Information: The Case of Pediatric Bone Marrow Transplant Caregivers

**Elizabeth Kaziunas**[1]**, Ayse G. Buyuktur**[1]**, Jasmine Jones**[1]**, Sung W. Choi**[2]**, David A. Hanauer**[2,1]**, Mark S. Ackerman**[1,3]

[1]School of Information, [2]Medical School, [3]EECS
University of Michigan, Ann Arbor
Ann Arbor, MI
{eskaziu, abuyuktu, jazzij, sungchoi, hanauer, ackerm}@umich.edu

## ABSTRACT

The impact of health information on caregivers is of increasing interest to HCI/CSCW in designing systems to support the social and emotional dimensions of managing health. Drawing on an interview study, as well as corroborating data including a multi-year ethnography, we detail the practices of caregivers (particularly parents) in a bone marrow transplant (BMT) center. We examine the interconnections between information and emotion work performed by caregivers through a liminal lens, highlighting the BMT experience as a time of transition and reflection in which caregivers must quickly adapt to the new social world of the hospital and learn to manage a wide range of patient needs. The transition from parent to 'caregiver' is challenging, placing additional emotional burdens on the intensive information work for managing BMT. As a time of reflection, the BMT experience also provides an occasion for generative thinking and alternative approaches to health management. Our study findings call for health systems that reflect a design paradigm focused on 'transforming lives' rather than 'transferring information.'

## Author Keywords

CSCW, health information, medical informatics, health informatics, caregiving, caregiver, pediatric, health and wellness, healthcare technology, reflection, social worlds.

## ACM Classification Keywords : J.3 Life and Medical Sciences, Health, Medical Information Systems; H.5.2 User Interfaces, User-centered design; H.5.3 Group and organization Interfaces, Computer Supported Cooperative Work

## General Terms
Design

## INTRODUCTION AND BACKGROUND

Bone marrow transplant (BMT) is used to treat a range of blood disorders and blood cell cancers such as leukemias and lymphomas. The procedure involves replacing unhealthy stem cells in the bone marrow with healthy ones harvested from the patient or a donor. BMT is often the only hope for a cure or for slowing down disease progress. It is an aggressive approach that takes a substantial toll on the patient's body.

Recipients constitute some of the most complex clinical cases due to the nature of the treatment and the serious risks it involves, the severity of the diseases for which transplant is done, and the heavy physical and psychosocial burdens. The BMT process is correspondingly challenging—clinically and emotionally—for patients and caregivers alike.

BMT, and especially pediatric BMT, is of considerable interest not only because the care process is so complex and difficult, but also because this setting offers critical insight into a number of wider sociotechnical healthcare issues being explored by the HCI and CSCW communities, such as supporting clinician-patient communication and managing chronic illness. As a growing number of specialized treatments are being developed for a range of health conditions, there is a need for patients and families (or in this case, parents and families), to access and understand clinical information in ways that are both expedient and meaningful. BMT differs from what is typically understood as chronic care in important ways – such as the amount of resources involved, including clinician time; however, it is similar in that BMT caregivers must collaborate closely with a team of healthcare professionals, learning the specialized language and the technical practices of medicine. Furthermore, as with many chronic illnesses, BMT intimately and profoundly shapes the everyday lives of patient, caregiver, and family.

In this study, we examined the lived experience for pediatric BMT caregivers. To do so, we considered the types of healthcare and interactional work caregivers and their families perform, and the meanings those activities hold for them. We found the high stakes of the pediatric

BMT process lead to considerable information work on the part of caregivers. Caregivers also engaged in a variety of emotion work to manage BMT. In documenting the interconnections between this information and emotion work, we found that the caregiving goals of families and clinical teams often misaligned, and that clinical information needed to be reconciled with the inclinations of a parent whose most pressing concerns may not necessarily coincide with the treatment protocol. The findings we present here therefore not only focus on the straight-forward information needs of caregivers, but also speak to the social tensions and emotional burdens that arise in managing a complex healthcare treatment.

We first discuss what is known in the CSCW and HCI literature about healthcare management at home, with children, and with caregivers (especially parents). We then discuss the framework we use in our analysis, that of Strauss et al.'s interaction work. We follow with a description of the site, our data collection, and the BMT process. Next, we present our findings about the information and emotion work parents do—detailed in terms of caregiving practices—as part of a process of moving from the social world of their everyday lives to a medical world and then back to a transformed everyday life. Finally, we explore the theoretical implications of the BMT caregiver experience, arguing that as people live amongst multiple social worlds, the relationship between clinical information and emotional inclinations needs to be understood as a negotiated activity, involving a form of labor that we call 'reflection work.'

## RELATED WORK

### Health Management in CSCW
There has been increasing interest in the CSCW/HCI communities to design systems that better support the social and emotional dimensions of managing a variety of health and wellness conditions [8, 9, 13, 14]. Furthermore, a number of studies in the CSCW/HCI literature have looked at the needs of parents in a variety of healthcare contexts as a space for technological support [6,12,19,20,23]. Although such studies have examined technologies to augment or facilitate consumer health, there are only a handful of caregiver-oriented ethnographic studies, especially of pediatric patients.

Important studies include Kientz [11], which examined the interactions between parents and pediatricians, describing tensions and challenges in this communication dynamic, including parents who had difficulty recalling and remembering details after consultation and asking questions of clinicians. Based on the study findings, Kientz recommended systems that help track information and include family members in shared health experiences via social media [11]. Toscos et al. [20] described how health-monitoring technology affects the parent-child relationship and highlighted the conflicts that can occur in the parent-

child relationship in caregiving work. In a study of caregivers and high-risk infants, Liu et al. [12] noted that currently little has been done to design collaborative systems for parents of pediatric patients. In their discussion of information-sharing challenges, Liu et al. pointed to social isolation as a problem for parents of ill children and suggested social support tools for networks of friends, family members, and health professionals.

In this work, we draw heavily on the contributions of Chen [3], and in particular, Chen et al. [4], which presented a qualitative study of caregivers and highlighted the need in CSCW and HCI to better understand the situated practices of caregiving in people's everyday lives [4]. Drawing on Strauss, the authors discussed the 'identity work' caregivers engage in as they manage multiple 'selves' (e.g. physical, emotional, and social selves). Furthermore, the authors found that caregiving is both a collaborative and reflective endeavor calling attention to the need for management in 'social-emotion work' and reflective learning. We seek to extend Chen et al.'s [4] work through grappling with the specifics of contextualized caregiving work.

### Framing Healthcare "Work"
In this paper, we draw upon the work of Anselm Strauss and colleagues for a general theoretical framing. Strauss contributed to many areas within health informatics and CSCW, the best known of which is articulation, or coordination, work. Strauss and colleagues [17, 18, 22], as well as Wiener et al. [22] and other related papers [17], described not only articulation work but also additional kinds of work in interaction and social activity in healthcare contexts. (For Strauss, and here in this paper, work is micro-interactional work, and is not necessarily conducted in formal workplace settings.)

Strauss largely analyzed the activities performed in medical settings by clinicians, such as safety work, or making sure that clinical processes wouldn't cause harm. As neither patients nor caregivers were the focus of Strauss' theoretical analysis, the two types of work in Strauss upon which we draw heavily for our analysis are 'patient-centered' in that they can also be performed by patients and/or caregivers. The first is sentimental work, also called emotion work; it is the intra- and inter-personal work involved in maintaining one's composure and self-control.

The second type is information work, which is generally under- theorized in Strauss et al. [18, 22]. Information work, as detailed in this writing, was premised on a conceptual model of straightforward information transfer that neglected to address social complexity. There has been a renewed interest in CSCW to articulate more contextually-situated understandings of information work [10, 15]. We follow these extensions of information work here, further contemplating the relationship between information and emotion work, in the intra-personal and

inter-personal labor involved in making sense of different types of information that we term reflection work.

## RESEARCH SITE AND STUDY METHODS
Our study was conducted at Hemphill Children's Hospital, a teaching hospital in the U.S. Midwest. Our specific site was the pediatric bone marrow transplant floor and clinic.

### Data Collection
Our data include 10 semi-structured interviews with caregivers of pediatric BMT patients. These data were also informed by approximately 10 hours of observing hospital rounds and pre-BMT consults by the first author. Observations included attending meetings between caregivers, patients, and clinicians, as well as informal conversations held among BMT team members that included nurses, doctors, dieticians, pharmacists, and social workers. Observational data were recorded as fieldnotes and later transcribed. Additionally the analysis of blogs and social media sites maintained by interview participants added to our understanding of the pediatric BMT experience. Five distinct websites (with a total of 371 distinct posts), shared with us by interview participants, were analyzed and used to triangulate our interview and observational data.

The interviews were conducted with primary caregivers for BMT pediatric patients. Study participants were recruited through referrals from the BMT clinical team and included caregivers at varying stages of the BMT process, although all participants had experienced the transplant procedure and at the time of the interview were being treated in the outpatient clinic. Interviews were approximately an hour and were recorded and transcribed; children were recorded with the permission of their parents. These semi-structured interviews took place in a conference room at the pediatric BMT center. Semi-structured interviews explored (1) The participant's caregiver experience with BMT, (2) everyday caregiving practices, (3) the impact of BMT on family life, and (4) information needs in the BMT process.

Interview participants included 6 mothers, 3 fathers, and 1 grandmother who acted as caregivers. Participants came from a wide range of socio-economic backgrounds and family structures. Some participants were single parents working full-time to maintain insurance coverage, while other participants had the support of two full-time adult caregivers for the patient. Some participants were from intact, nuclear families; others were not. Age and education also varied as a number of caregivers had little or no higher education while others had several degrees and professional training in the sciences. We acknowledge that such demographic data shapes the BMT experience, and in this paper we have limited ourselves to reporting findings commonly articulated by caregivers across demographics.

During the interviews, additional family members and occasionally children going through the BMT process, would join the conversation and provide insight. While caregivers were the main focus of this study, we routinely observed an intimacy in the communication between children and their caregivers to the point where they would often finish one another's sentences. While acknowledging the child's role as a BMT patient as a unique experience unto itself (caregivers, in fact, often deferred to the patient's interpretations of medical events), it is also important to note that participants often spoke about the BMT experience in terms of "we" and "our family." This collective language perhaps points to the deep social impact of BMT and the close relationship between parent and child amplified by long days spent together in the hospital and clinic.

Our work has also been informed by a larger research project aimed at understanding the BMT experience. We also have conducted 3 focus groups of 26 individual participants involved in BMT that included 6 caregivers of BMT pediatric patients as part of a study (led by the fourth author), and a 2-year ethnographic study of adult BMT (by the second author). IRB approval for data collection was obtained along with participant consent.

### Data Analysis
Our data analysis followed grounded theory [5,7] in that our data collection and analysis mutually informed one another. Four initial interviews were transcribed and analyzed using an open coding method by each researcher to identify significant concepts. These coded interviews were then discussed among four of the authors to ascertain main issues; for confidentiality reasons, only the non-medical researchers could see the raw data. During data analysis we collectively generated new codes as significant concepts were identified, compared, and revised. These codes were later used as probes in subsequent interviews. The second stage of data analysis with new data resulted in consistent themes and confirmed our findings. Fieldnotes and blog posts were read, coded, and analyzed in a similar manner during data analysis sessions. Analytical memos were also circulated and discussed among the group as theoretical insights emerged from the ongoing data collection.

## BONE MARROW TRANSPLANT BACKGROUND
The BMT process can be viewed in three overarching stages: pre-transplant, transplant, and post-transplant. Patients are first admitted to the hospital for pre-transplant conditioning therapy, high doses of chemotherapy sometimes along with radiation therapy, in order to wipe out the patient's bone marrow and destroy diseased cells. During transplant (commonly referred to as "day 0") new cells are then used to rescue the marrow. Unlike solid organ transplants, a bone marrow transplant is not a surgical procedure; the stem cells are infused much like a blood transfusion and find their way to the patient's marrow spaces. The transplant is, in itself, painless and anti-climactic; the emotional and physical toll comes later.

Because chemotherapy wipes out the patient's bone marrow and blood counts become very low, for a while the patient is dependent on red blood cell and platelet transfusions. Since white blood cells are killed off, the patient is also at risk for infections that can be life threatening. The patient is placed on a strict regimen of antibacterial, antifungal, and antiviral medications to prevent potential infections. Patients remain in the hospital on average 2 to 4 weeks while they wait for the transplanted cells to grow and produce new blood cells. This process is called engraftment and is generally acknowledged as an anxious period of waiting for the patient, family, and clinicians alike.

The patient remains in the hospital at least until engraftment occurs. Absent complications, the patient is discharged from the hospital (often referred to as "day 30"). Since the patient is placed on anti-rejection medication for months, however, the risk for infections continues for much longer.

### Clinical Challenges
The most feared complication from BMT is known as graft-versus-host disease (GVHD), which results from donor cells recognizing the patient's body as foreign and attacking it. Acute GVHD usually occurs within the first 100 days post-transplant, whereas chronic GVHD tends to emerge later and last longer, sometimes for the patient's lifetime. Although the location and severity of GVHD varies, acute GVHD commonly affects the skin, gut, and/or liver.

GVHD must be diagnosed and treated as early as possible in order to prevent it from getting rapidly out of control. Since GVHD results from the donor's immune cells attacking the patient's body, the standard treatment is steroids and/or other immunosuppressive drugs, sometimes in high doses. One of the main challenges is that the immunosuppressive medication used to prevent and treat GVHD also makes the patient more prone to infections.

In addition to infection risk, long-term steroid use can cause complications such as osteoporosis, high blood sugar, and adrenal insufficiency (where the body quits making a sufficient amount of steroids on its own), among others. Even short-term steroid use may have side effects (e.g. mood swings or high blood pressure). The side effects or adverse effects are managed using additional medications.

A BMT patient can often be on 15+ medications at a time, taking many of them several times a day, for many months. Side effects from medications and any co-morbidity that the patient has must be managed. The ultimate goal is to get the patient off all immunosuppressives and other medication that is not needed. The balancing act is challenging; and to the caregiver, at times it seems as much an art as science.

Given the need for close monitoring, if the family lives too far away, then the patient and a caregiver must find a temporary residence for the first few months as an outpatient (commonly until day 100) somewhere close to Hemphill. The BMT physician and clinical team see the patient and caregiver in the outpatient BMT clinic during this period as often as twice a week. The interval gradually increases based on the patient's progress, going to once a week, then every two weeks, and so on. The child is closely monitored by the team for at least 1 year, but often longer.

### The BMT Care Team
At Hemphill, each patient remains under the care of one primary BMT physician throughout the transplant process, however, a large number of other clinicians and medical staff are also involved, first during the stay in the hospital and then again as outpatients in the clinic. During daily rounds in the hospital, for instance, parents and patients meet with a team of medical professionals that includes an arrangement of physicians, nurse practitioners and nurses, physical therapists, dieticians, pharmacists, and social workers, among others. Some of these clinicians remain constant through a family's stay in the hospital, while others rotate through the hospital ward every two weeks. In outpatient care, parents work with the primary BMT physician as well as other clinic staff such as physician assistants, nurse practitioners, and infusion nurses.

The BMT clinicians, both in the hospital and outpatient clinic, come to know the patients, caregivers, and often their extended families very well. We have been consistently impressed with the level of care and commitment that the BMT clinicians demonstrate. Several team members (including physicians) have noted how important it is for them to interact with their patients and their families on a personal, as well as clinical level.

*Role of the Caregiver*
It is significant to note that a parent, as caregiver, is required to stay with the patient, essentially 24/7, during the first 2 to 3 months following hospital discharge or as long as medically required by the BMT physician. In fact, in this hospital no transplant is approved without a satisfactory and formal caregiver plan. According to hospital policy, it is acceptable for the caregiver role to be fulfilled by multiple people; however, usually only 1 or 2 people (almost always a parent) perform these duties for pediatric patients.

In the first year of transplant, much of the caregiver's time is spent in clinical settings involving visits with the BMT team and other specialists, various tests and procedures, and blood transfusions or other infusions. Once the patient is discharged from the hospital following transplant, much of patient care falls to the caregiver. These include managing medications, infusions, and sometimes injections; following infection precautions and, adhering to dietary and lifestyle restrictions. Much of normal life is put on hold. Arrangements must be made with school and employers, and social life is severely limited.

In all, the transplant is an exhausting process physically and mentally. There are also significant emotional challenges with the BMT process. This is true not only for the patient

but for the caregiver(s) as well. The treatment is highly technical and demanding, which brings with it anxieties about understanding critical health information and how well one will be able to cope with pressing day-to-day concerns. There is also much uncertainty about the future and fear associated with these unknowns.

## INFORMATION AND EMOTIONAL CHALLENGES

We now turn to the caregiver experiences with information and emotion work during the BMT process. Throughout the BMT process—from hospital to home—caregivers engage in a wide range of information and emotion work that is necessary for the child's welfare. We note that although information work and emotion work can be analytically separated, in practice, these two types of work are often inextricably linked.

### Clinical Information Work

Clinical information work includes tasks such as learning how to perform medical procedures, understanding and organizing medication regimens, tracking a child's diet, fluid intake, exercise, and bowel movements, interpreting blood counts, researching treatment options and medication side effects, and becoming adept at conversing with and questioning medical professionals.

Participants described "following protocol" in relation to the various medication and treatment regimens as generally "overwhelming," even in the best of times. For the majority of our participants, clinical protocols were viewed as important to understand and follow closely (often as a matter of life or death). A mother explained:

*Everyday we're still very cautious about, you know, follow[ing] what they tell us to do to the "T" or we try to at least. We don't want any setbacks.[P-03]*

Participants expressed that this information work, especially in the initial weeks, took a great deal of attention, diligence, organizational skill, hands-on training and medical terminology so as to perform the necessary tasks.

#### Learning at the Hospital: Pharmaceuticals and Procedures

The weeks spent living at the hospital during the BMT procedure was spoken of by caregivers as a rich informational experience. It was during their hospital stay that they learned the skills and knowledge needed to do medical tasks. While there were varying levels of training offered to caregivers before discharge, our participants pointed to the informal education they received through watching and chatting with nurses day-to-day. One father discussed how he and his wife learned through careful observation of the BMT clinical team:

*I pay attention to everything, and my wife is the same way, with what they are doing…You just learn by watching, it's just repetitive nature. [P-06]*

Participants also received more direct instruction from clinicians. For example, many caregivers in the study informed us that they learned proper line care, medication regimens, and wound care through promptings and encouragement by the nursing staff. A participant explained how nurses provided both her and her spouse with hands-on line care training at the bedside of their son who had a catheter inserted through the veins in his chest.

*Like with flushing his lines and stuff like that; you know, cleaning when he had his NeoStar…When we were in the hospital, the nurses … they were always asking, "Do you want to do this?" They'll watch you and train you like right there. Changing the bandages and stuff. [P-02]*

Another caregiver explained how nurses in the hospital trained him to administer his child's medication regimen so that he could continue to follow it when the family was discharged and returned home.

*And as he [child] got further along through the process, they had you make sure--he had like six or seven oral medicines to take each day--and so, they made you do it, well, they give you the option. They ask the parents to do it…. We had to do it at a certain time each day. Some of the pills were time-sensitive; some of them just were day pills. So that routine is what we still follow. [P-08]*

#### Attending to the Child: Charting and Tracking

On leaving the hospital, caregivers are charged with tracking the patient's food, fluid, and even bodily emissions like urine and bowl movements. Parents also kept track of changes in a child's skin texture or color, sleep patterns, and energy levels. A participant explained about her son:

*I pay attention to everything that is done with him, every movement … Any bruise, any mark, you know, he doesn't even have to have labs done for me to tell you if his platelets are low. [P-09]*

This information is important, as the patient needs to maintain specific caloric and fluid intake not only to avoid malnutrition and dehydration, but also to prevent complications, such as GVHD. One participant explained that the high risks of complications associated after the BMT require hyper-attention and discipline in tracking:

*People don't die from the transplant, I feel like. I think a lot of times it seems like they have like the secondary things that come with it, the infections and all those things. It's very, very hard to be…not that I'm tooting my own horn … but it's hard to be disciplined in those things. [P-05]*

This type of discipline and training, though, begins in the hospital as caregivers are provided official forms to guide aspects of this work. For instance, one participant noted how he and his wife first started recording nutritional information for their child during the inpatient process:

*We had to write down what they were eating, how much they drank … In the hospital they dropped off a sheet every day, a nutrition sheet, and we just filled it out. [P-06]*

When they return home, the responsibility of tracking is left to the caregivers. One participant, a mother, noted that the labor involved with such detailed tracking is like a full-time job that she and her husband did together. They also noted that it became "a way of life":

*It's almost like a job every day, because you're taking medicine four different times of the day, ... writing down what you eat every second, keeping track of, you know what I mean, everything! Even the water he had to drink, like two liters of water per day ... We needed to track and make sure that he was going to the bathroom enough ... It just becomes a way of life. [P-02]*

**Sentimental/Emotion Work**
Participants, not unexpectedly, experience a great deal of fear, anxiety, and stress throughout the BMT process due to the uncertainty of the procedure's success (e.g. child's ability to engraft new cells) and risk of potentially fatal complications (e.g. infections and GVHD).

All of our caregiver participants describe the frustration, anxiety, and even panic felt when trying to replicate medical regimens at home. One overarching concern was remembering how to do line care properly. Line care involves cleaning the lines of the child's implanted port or doing IV infusions. "It was nerve wracking!" was a common refrain among caregivers, especially in the first weeks at home. One participant noted the risk involved:

*It's scary. That line goes right into your child's heart. ... I'm not a doctor or a nurse, but you have no choice, so you do it. [P-05]*

A grandmother, who acted as a caregiver for her grandson a few days a week, struggled to remember all of the steps involved in line care. During the interview she expressed feeling at times guilty and inadequate for not being able to remember these important details:

*It was learning how to do all that IV stuff. I was nervous, very nervous ... I had a hard time remembering. It's like he [the grandchild] had to talk me through it ... [P-01]*

Another major challenge of caregiving described by our participants was dealing with the medication regimens. It was often difficult, for instance, for caregivers to keep track of the large number of medications prescribed to their child and the times at which each needed to be given. All the caregivers articulated designing elaborate organizational charts and routines to help them remember the ever-changing details of medication.

One often repeated difficulty was trying to get children to swallow the necessary large number of pills prescribed. Participants used expressions like "exhausting" and "hissy fits" to describe how time-consuming and emotionally draining these events were. For example, one father found his 7 year-old son hiding his pills because of the unpleasant taste and side effects.

*So we actually have to physically watch him take his pills ... I don't blame him, I wouldn't really want to take them either ... They don't taste good ... I'm a blunt person, so I just told him, "You want to die? This is how serious it is." And he cried or whatever, but we still make sure we watch him take them and let him know how serious it is. [P-06]*

Another caregiver father echoed similar struggles with getting his 10 year-old child to take his medication. Unable to swallow pills, the family tried liquid versions unsuccessfully before eventually resorting to the placement of a Nasojejunal Tube, which runs from the nose into the intestines to inject the medication. He describes this as a "battle" that could last hours.

*I mean, literally ... it would take 12 hours sometimes to get him to take his medicine, but he would always take it. And it sucked. It sucked really bad, really bad. You don't want to fight with your kid about anything. [P-08]*

All these daily trials appeared to feed into a constant anxiety for our participants, especially as they contemplated the uncertain outcome of the procedure. As one mother of a 5-year-old boy explained, caregivers must constantly navigate the "unknown."

*The unknown. The most difficult part of the process, because it's a life or death process. That's the most difficult part. And do you want to subject your child to chemo? And will your child survive? What type of complications will he face? Is it worth it? Does the benefits outweigh the costs? That's the most difficult thing, is the unknown. [P-03]*

Along with concern about future outcomes and the day-to-day, the caregiver's near constant state of anxiety also needs to be managed. This is often dealt with by clinicians during rounds or clinic visits. Parents were often legitimately concerned about prescribed drugs or curious about alternative treatments, and look to clinicians for both information and assurance. Despite their best intentions, the medical staff cannot always provide the necessary time or offer the certainty that the anxious caregiver longs to hear.

**Connecting Information and Emotional Work**

*Managing Burnout: Talking with Other Caregivers*
Despite the BMT team's considerable efforts, the clinical process takes a heavy toll on the caregivers and on the family as a whole. Many participants noted they try to remain strong for their children and deal with their stress silently. When we asked one how she manages her life as a caregiver, she responded that she simply has not stopped 'going' since her son's diagnosis of leukemia 3 years ago:

*I don't know how to answer that. I think God gives you the trials he gives you for a reason. This was just one I was made to handle. I mean honestly, [participant tears up and speaks in a distraught voice] I don't know ... there are other parents that have cried on my shoulder ... I just keep going. I don't know how or why ... I don't know. [P-02]*

Many participants echoed the need to "keep going" and "put one foot ahead of the other," but they also mentioned the connections and strength they drew from other BMT caregivers. At the hospital or clinic, caregivers chatted with each other in the halls or waiting rooms sharing stories and offering support to one another.

One participant, a father whose daughter had a bone marrow transplant, recounted his family's friendships with other BMT caregivers. One of these families became trusted guides that helped them adjust to life in the hospital:

> They said, "Oh, this is how you can survive at the hospital." Because they had been here ... like buckets of toys by the windowsill. How do you survive the hospital room for months at a time? [P-08]

Along with offering emotional support, caregivers also tried to help each other manage "the unknown" by sharing their experiences with particular medications or medical procedures. One participant spoke about the close relationships with other caregivers:

> And even across diseases, making friends with families and knowing where they're at and their struggle ... you know everybody, and know who's dying and who's not dying ... And so while the kids play Legos, mom and dad sit and talk: "What drugs your kid on? Watch out for Reglan [type of drug]!" You know, "Don't ever let any family member get Reglan." "Why?" "Well the old docs love to prescribe it, but it can destroy your bladder." [P-07]

### Extreme Protocols and Creating Artifacts

Parents who were not socially inclined found other ways of coping. Sometimes this took the form of performing tasks that went past the already rigorous recommendations of the clinical protocol. A few participants, for example, spoke of doing extensive remodeling to their home. These families installed new flooring, repainted, and threw away furniture in an effort to eliminate germs, mold, and dander that might negatively impact their immune-suppressed child.

One participant, a mother of an 8-year-old patient, described her cleaning regimen as "extreme" noting that she and her husband researched extensively how to minimize risk of infection on the Internet and "ran with it."

> We might be extremist... [We have] no carpet in our house, no fabric curtains. I mean, if there was anything that could be done, that's what we did.... And I think we took every bit of information that we found and we ran with it. You know, new furniture, nothing on the walls. I mean, I washed the walls every day; there was no dust. It was insane. [P-05]

As the interview progressed, the same participant noted that this flurry for research and cleaning also reflected her family's emotional state, noting, "Maybe that's how we coped ... I think it's probably a coping mechanism for us, now that I think about it." [P-05]

There were many parents who took on the role of biographer of their child's medical experience. Along with capturing images and videos of their children visiting with relatives or celebrating a birthday in the hospital, caregivers also often took photographs related to medical procedures from transplant itself to routine line care activities to bags of blood and pill containers. Other common subjects included documenting potential medical problems like a rash on the skin. Many of our participants also noted how they routinely collected and shared clinical information artifacts, from photographs of a nurse's scribbled notations of a patient's blood work counts on a white board to a doctors' hand-drawn diagram of GVHD, through blog posts, Facebook page updates, and various social media.

Often these information artifacts were deeply meaningful to the caregivers and their families as testaments to particular moments of triumph or loss. These artifacts have a practical importance, but their symbolic nature is critical to our participants. Indeed, we have seen many small, ritual-like interactions with information artifacts in much of the caregiving work performed by parents.

So far, we have discussed a number of complex information and emotional challenges for BMT caregivers. Some of these difficulties are also encountered in a range of other health conditions, such as medication issues and the need to emulate clinical regimens. The nature of BMT, however, draws out the emotional issues and highlights ways in which information is often invested with additional symbolic meaning(s). These issues are, moreover, framed by two critically important contextual characteristics of BMT: the transitions between social worlds and engaging with a multiplicity of logics. We turn to this next.

### Navigating Between Social Worlds

The first days at Hemphill Children's Hospital often elicit hopeful feelings among BMT caregivers. The transplant is often a last resort for treating terminally ill children and represents the chance for a healthy life for the admitted child. Many of the obstacles families have faced—from the child's chemo regimens to finding a willing and healthy donor match—have at this point finally been overcome.

This cautious optimism for most families, however, was quickly tempered by the pressing cognitive, physical, and emotional demands that come with their new reality of living day-to-day on the hospital floor. Due to the length of the inpatient stay, families are informed by BMT staff to expect considerable disruptions to family life. Caregivers are often separated from significant others and other children in order to stay in the hospital. This separation can last even longer if the caregiver needs to geographically relocate near the hospital while the child is an outpatient. At times, these household disruptions can be quite emotionally burdensome. A mother from out-of-state explained:

> There's five in my household. ... We have two other kids, 17 and 15. So I'm leaving kids in the highlight of their high school year ... I miss my husband, my older son, and my youngest daughter ... Medical stuff ain't nothing. [P-02]

It should also be noted that learning the "medical stuff" is far from trivial as it requires an in-depth knowledge of the healthcare system. Early on in their BMT hospital stay, all of our participants described challenges in their communications with doctors who relied upon technical medical language. During rounds, for instance, one participant noted that doctors would speak "book talk."

> *All the fellows [physicians] would be all like book talk. "Oh, your creatinine levels are at such and such." I'm like, "Excuse me?" They're like, "Liver is doing fine." [P-10]*

As caregivers lived on the hospital floor, they came to understand more medical terminology and gain confidence in communicating with and questioning clinicians. This confidence was especially important during rounds, a time when caregivers and patients met with the core BMT team to share information and get feedback on the child's status. During this brief daily interaction, caregivers felt the need to have questions formulated in advance in order to competently speak to the BMT clinical team. Participants likened this experience to preparing for class:

> *So I suppose it's a learning curve ... We didn't know Day 1 what to track. And there are times we are just dead wrong. We were talking about cholesterol when LDH is not cholesterol, it's acid created by your muscles when they are injured. At the time, I was thinking ... you know, one kind of cholesterol and then there is the other kind of cholesterol. Like, no, that is not what it is. [P-04]*

### The life of having a sick child"

After transplant, caregivers began to adapt to their new daily existence of medication regimens, lack of sleep, and anxiety that make up their hospital life. Holidays, birthdays, and anniversaries come and go while in the hospital. A family whose child had severe GVHD described their "new normal" as a family disrupted:

> *This starts the sixth week of admission. The walk to the car is getting longer and the camaraderie with the nurses grows, because this is the new normal. The life of having a sick child, the life of a sick child. [P-07, blog entry]*

As caregivers adjusted to life on the floor, they found ways of bridging the space between social worlds. They talked to other parents over endless cups of coffee, connected to family with Skype, and learned the new routines and rhythms of the hospital.

The caregivers' experience of BMT is often quite different from that of the clinicians', even when medical work is collaborative in nature. This is reflected in the important routine of blood work, as caregivers wait for the daily blood counts to be returned from the lab to see if the BMT process is working (or not). To explain how significant blood work is on the hospital floor, a participant explained, *"Every person's day on 3North revolves around blood products." [P-07, blog entry]*

Caregivers collect blood count lab results verbally from the medical staff during rounds or from nurses on the floor. Observing rounds, we watched as parents asked eagerly about "the numbers" and waited with clasped hands for the answer. Blood counts for BMT patients can often go up and down significantly in a matter of days. If blood counts that day are "good" according to the doctor's interpretation, parents might clap and cheer, as a sign they might be discharged soon. If blood counts are lower than expected, the caregiver waits patiently for the next round of tests.

Blood work numbers are hand-recorded on a large calendar hung prominently in each room, individualized with the child's name across the top. Parents also routinely create their own information artifacts around blood work, posting updates and photographs through social media.

### Going "Home"

When a child's blood counts rebound and the medical team deems the child ready to leave the hospital, it is cause for celebration. Due to the extensive follow-up outpatient appointments, however, families must remain located within commuting distance. Even local families, however, never really go 'home,' at least as existed pre-BMT. The child is now also a 'patient.'

As mentioned, the transition between hospital and home also heightens anxieties for caregivers as they take on the routine medical work once performed by nurses in the hospital. Many participants described this anxiety:

> *It's just like when you have your first child, and when you first leave the hospital, it's kind of scary, but you've got your in-laws or your parents usually to fall back on. Well, you ... don't have that. [P-06]*

Although caregivers are trained by medical staff to perform routine tasks like cleaning incisions and doing IV magnesium infusions, caregivers often still expressed being overwhelmed because the risks were so real. The sentiment in the following quote was echoed by many participants:

> *I was just scared...scared that you are going to do something wrong. Am I going to remember everything that ... that I have to do? What if I forget to do this and he gets sick, or I don't do it right? Those are the scary things. [P-04]*

Indeed, one mother told us she did not want to leave the hospital at first to go home, uncomfortable returning to her former life without the "backup" of the medical team.

Our participants reported that their family life changed dramatically. Children who had the BMT procedure often had to be kept away from friends for fear of infection. One 8 year-old girl recalled going home:

> *[C]ertain people could come in the room and everyone else had to stay out. They could talk to me through the screen door. "I love you from a distance." [P-12]*

The risk of contracting a cold or flu from others can leave the family isolated from their previous worlds. Another caretaker described how this isolation impacted her family:

*And even when you go home you're kind of secluded because like we disinfected the whole house ... you don't really have visitors. You don't have family over because they could potentially have a cold or a virus that they don't even know of ... [I]t stays that way for like the first whole year. [P-04]*

The experience of being between social worlds may continue on going home as friends and extended family cannot grasp the new reality of the caregiver and patient.

## Transformations: Engaging with Multiple Logics

Medical tasks require the BMT caregivers to collaborate closely with a team of clinicians, learning much of the specialized language of medicine and the technical practices of care. As our findings demonstrate, information in such a health context is never solely clinical. It is grounded in the moment of life and death choices, sleepless nights in the hospital, the frenzied washing of walls, and ritual archiving of blood counts. Clinical work sometimes combines a range of logics and is at times in tension with the other inclinations and concerns of a parent seeking to provide a child with a whole and happy life.

A common competing logic found in BMT is found in the attitudes and practices around alternative therapies, exemplified by 'June', a mother who pressed the BMT team for the inclusion of alternative therapies in her 11-year-old daughter's treatment regime. During rounds, June asked the physician about her daughter's blood cell counts. She worried about how long engraftment would take and the doctor told her they would just have to wait and see whether the cell counts grew. June looked anxious after this pronouncement and asked about supplements, such as mushroom teas. June explained to the medical staff:

*I have special teas too. I know you doctors don't believe in all of this, but I see her every day and her energy level goes up. There is nothing you give us to build back the immune system, to strengthen the immune system.*

The pharmacist on the BMT team responded to June's queries with concern, explaining that mushrooms could cause fungal infections and other supplements might contain problematic ingredients such as human growth hormone. While a parent naturally wants to try anything to help build their child's immune system, many alternative treatments could be harmful immediately after transplant. The BMT team acknowledged they understood the caregiver's desire to try to find things that would help June's daughter, explaining:

*We don't mind reviewing everything with you at clinic. Just bring in the box or package. We know that it can be important to the families. I don't have a problem with it; but, we just ask that before you take it, you talk to us first.*

Another important logic for caregivers in our study was tied to the experience of being a parent. Many of our participants, especially those who have had years in and out of medical facilities, spent considerable time reflecting upon how different treatments affect their child, not just medically, but as a human being. These caregivers weigh clinical information from the BMT team against their past experiences and insight from other families, often carefully deliberating treatment decisions with a range of more humanistic concerns, such as quality of life.

One of our caregiver participants, 'Martin', was a father whose 10-year-old son received multiple transplants. Martin started out full of optimism during the first BMT, learning complex medical terminology with enthusiasm and having high hopes for the procedure. His family strove to follow the clinical treatment protocol. After watching his son go through two rejections and spend multiple birthdays in the hospital, however, Martin found himself weighing clinical protocol against his son's deep desire for a "normal life". We recount his family's BMT story, one of three transplants and countless hard decisions:

*The first two transplants were really, really difficult. We went through a lot to decide to do the third. He [Martin's son] was prepared to die. He knew the ramifications of not having the third transplant and would rather have died then go through that. But then he got a taste of school and wanted nothing more than to go back to school even if it was for a short period of time. And so we did the third transplant ...*

*They told us we couldn't have pets because it would cause an immune system problem. But here you have a child who has a 6% chance at living, and the docs just sent him home and said, "You can't go to school and we don't know when you will be able to because you are so immune compromised." And so, what do Mom and Dad do? ... We got a beautiful German Shepherd dog ... He's just the best dog ever and my son's best friend ... And we haven't had any problems.*

Martin reflected on his BMT experience, noting that he has found himself engaging a range of different logics. The clinical information is always considered when making decisions about the management of his son's condition, but it does not necessarily trump being a father, as he noted:

*But again, the human perspective versus the textbook perspective is two very, very different things.*

In this narrative, the daily trauma of being a caregiver, as expressed by this participant, is one of warring sensibilities between fighting for survival and easing suffering: Will my child's present pain be worth it?

These competing logics operate alongside, against, and with the logic of medicine. Practices like documenting blood work are grounded in a kind of embodied 'ritual logic' that may offer solace and hope. Other logics, such as those that argue for alternative therapies, make sense for parents, but perhaps not for clinicians. Information work and emotion work are understood by families within these logics.

## DISCUSSION

Above, we presented the challenges for our BMT caregivers and described the important practices they adopted to fulfill their roles as caregivers. In summary:

- Our participants learned important caregiving practices from the members of the clinical team, especially nurses. Nonetheless, they often found themselves struggling to understand what they needed to know at different points in the BMT process.

- Our caregivers found themselves under intense psychosocial burdens, which include anxiety, stress, exhaustion, and isolation. The BMT process requires 24/7 care and at times is very stressful due to the high risks involved. It requires the caregiver learn a great deal about medical issues very quickly, and there is considerable anxiety about performing well. Furthermore, the caregivers are exhausted and socially isolated because of the demands of caregiving.

- For our participants, information often came in forms (and at times) that required emotional work. As well, emotionally critical times often fostered information needs. Information work and emotional work, then, were often intermingled, and were often not separable in actual practice.

- As a way of managing the challenges that come with the intermingling of information and emotional work, our participants developed coping strategies including interacting with other caregivers, creating symbolically rich information artifacts, and implementing extreme health management protocols.

In our analysis, these challenges, information work, and emotion work described by our participants appeared to be grounded in three central characteristics of the BMT caregiver experience: (1) the inherent connection of information and emotional work, (2) the transitions between the social worlds of hospital and home; and (3) the engagement with a multiplicity of logics from different social worlds needed to manage this health condition.

We now turn to unpacking the implications of these characteristics and discussing how such insights can help extend the design of health-related systems. First, as we have noted repeatedly, information and emotional work were not always separable in practice (e.g., [15]). Information work created emotional work, emotional work created information work, and often the two happened at the same time. Understanding how information transfer occurs in practice will be extremely important in creating useful and usable information sources for these patients.

Second, the hospital is its own social world [18], a community with its own roles, norms, language, and even rituals. Leaving home and moving into this new medicalized social world can be understood as a liminal experience, characterized by being transitional states or situations. Victor Turner and others have pointed to the

social significance that transitions between social worlds (marked by rites like weddings, pilgrimage, coming of age ceremonies) have in people's lives. Turner's conceptualization of liminality, rooted in the study of rituals, highlights how that movement can be profoundly meaningful, and at times even transformative. Turner characterizes the liminal as a period of ambiguity and uncertainty (a place between and betwixt) in which people are not held to the norms of their other social worlds [21]. During ritual events, for instance, the liminal period is an essential stage in which people move from a state of the uninitiated to being transformed. For Turner then liminality is both a period of time and a process.

In our findings, we saw our participants, too, necessarily going through a transformative process. That is, our caregivers often did not start knowing medical jargon and procedures. (The exceptions were those caregivers whose children had been through chemo regimens already.) Our participants had to become 'caregivers' and as they did so, they lived in a space that was no longer of the everyday, but also was not a clinician's professional world.

The transformation into a formal caregiver is only one aspect of the BMT's liminality. Tuner noted that the liminal is also a period of reflection and generativity in which people are exposed to new ideas, question dominant knowledge paradigms, and reshape their understanding of the world. In this way, through documenting blood work, questioning clinicians, and talking to other families, we saw parents transition into caregivers, coming to understand 'medicine' and 'home' in new ways.

Understanding liminality as a process allows one to understand how information work and emotional work change for caregivers over time. The transition between the social world of everyday life and the social world of a family with a patient requires many transitions and stresses. Knowing the rhythms of these changes will be critical to understand.

This also extends the concept of social worlds. For Strauss and colleagues, people obviously move among social worlds. How they do so is not specified (although Charmaz [2] details some of this in her examination of how people come to understand themselves as having chronic conditions). This extension to social world theory will allow a better-grounded examination of the micro-details of the transition process, as well as the information and emotional work required for BMT. We believe this theoretical extension will also be valuable for caregivers and patients in a large range of chronic conditions.

Third, the theoretical framing of liminality makes visible the work involved in navigating the multiplicity of logics and counter-intuitive logics inherent in differing social worlds. What looks like intransigence or even anxiety on the part of caregivers may be better viewed as ongoing navigation, reconciliation, and even superimposition in

progress. In this view, information work and emotion work in BMT are part of processes in which people make connections between differing logics (reconciling them) or generating alternatives (challenging or even rejecting a dominant logic). Indeed, from the viewpoint of Turner, being pushed outside of one's previous social world presents parents the opportunity to reconsider commonly held understandings and generate "novel configurations of ideas and relations." [21].

This is micro-interactional work in its own right. Drawing on the theoretical framings of Turner and Strauss, 'reflection work' can be seen as the labor involved in managing the utility of both information and emotional work when a person is confronted with differing social worlds. (We note that some of our caregivers were also confronted with viewpoints from alternative medicine, such as those believing in herbal remedies, or from faith-based beliefs.) Our findings point to the potential augmentation of this reflection work as a way to motivate and further the medical work, while maintaining a tie to the caregivers' other social worlds) in the design of health management tools and systems.

## CONCLUSION

In this study, we tried to open the box of micro-interactional work to include both a nuanced view of information and emotional work. We believe this work offers several important contributions. At a theoretical level, it extends Strauss' theories about information work, and details how two important kinds of Straussian micro-interactional work (information and emotional) are related. Previous CSCW work has pointed towards that relationship and its importance to users (e.g., [14, 15, 16] and even [1]), but our work here points towards the centrality of how information work and emotional work was combined for our participants.

As well, we have pointed to Turner's liminality as process. We showed its usefulness in understanding how caregivers must both transition between social worlds and manage the differing logics among social worlds. Seeing information work and emotional work as part of a transition process will be helpful in demarking phases of patient and caregiver needs.

We have shown that some of the issues in BMT information work result from the medical disease and treatment. However, we also showed that a considerable amount is the result of participants' needing to navigate between different social worlds, some of which were unknown at first or even conflicting, in this liminality process. For example, we noted that understanding medical terms and the medical viewpoint requires considerable information work and can also require emotional work.

Our work also offers important implications at a practical level. Our basic goal was to understand how to support pediatric BMT caregivers in their role. In this paper we analyzed the caregiver role, following the lead of Chen, and we focused on their information and emotional work. We showed how information most needed by the pediatric BMT caregiver has to be contexualized and situationally understood (as has been found in many CSCW studies). It is almost impossible to do this by oneself, and caregiving tasks often require scaffolding and collaborative assistance. More importantly, since information and emotional work are intertwined, we believe that what might be understood as information transfer is secondary to supporting the processes of bringing people more comfortably into adopting very new life circumstances. The design of tools and support to do so will be critical. Our future work will extend the analysis presented here to new prototypes that incorporate these findings. We plan to carefully examine the kinds of scaffolding we can present to caregivers that combines information and emotional work. We also plan to examine the rhythms of the transition caregivers make to understand their new world.

## REFERENCES

[1] Ackerman, M.S. Augmenting organizational memory: a field study of Answer Garden. *ACM Transactions on Information Systems*, 16, 3 (1998), 2013-224.

[2] Charmaz, K. *Good days, bad days: The self and chronic illness in time*. Rutgers, New Brunswick, NJ, 1991.

[3] Chen, Y. Health use in chronic care cycles. In *Proc. CSCW 2011*, 485-488.

[4] Chen, Y., Ngo, V., and Park, S.Y. Caring for caregivers: Designing for integrality. In *Proc. CSCW 2013*, 91-102.

[5] Corbin, J.M. and Strauss, A.C. *Basics of Qualitative Research*. Sage Publications, Inc., 1998.

[6] Farnham, S., Cheng, L., Stone, L., Zaner-Godsey, M., and Hibbeln, C. HutchWorld: Clinical study of computer-mediated social support for cancer patients and their caregivers. In *Proc. CHI 2002*, 375-382.

[7] Glaser, B.G. and Strauss, A.L. *The discovery of grounded theory*. Aldine, Hawthorne, NY, 1967.

[8] Grimes, A., Landry, B., and Grinter, R.E. Characteristics of shared health reflections in a local community. In *Proc. CSCW 2010*, 435-444.

[9] Huh, J., Patel, R. and Pratt, W. Tackling dilemmas in supporting "the whole person in online patient communities. In *Proc. CHI 2012*, , 923-926.

[10] Kaziunas, E., Ackerman, M.S. and Veinot, T.C.E. Localizing chronic disease management: Information work and health translations. In *Proc. ASIST 2013*, 1-10.

[11] Kientz., J.A. Understanding parent-pediatrician interactions for the design of health technologies. In *Proc. IHI'10*, 230-239.

[12] Liu, L.S., Hirano, S.H., Tentori, M., and Cheng, K.G. In *Proc. CHI 2002*, 1-8.

[13] Liu, L.S., Huh, J., Neogi, T., Inkpen, K. and Pratt, W. Health vlogger-viewed interaction in chronic illness management. *In Proc. CHI'13*, 49-58.

[14] Mamykina, L., Mynatt, E., Davidson, P.R., and Greenblatt, D. MAHI: Investigation of social scaffolding for reflection thinking in diabetes management. In *Proc. CHI'08*, 477-486.

[15] Mentis, H., Reddy, M., and Rosson, M.B. Invisible emotion: Information and interaction in an emergency room. In *Proc. CSCW 2010*, 311-320.

[16] Prilla, M., Degeling, M., and Herrmann, T. Collaborative reflection at work. In *Proc. GROUP 2012*, 55-64.

[17] Strauss, A., Fagerhaugh, S., Suczek, B. and Weiner, C. Sentimental work in the technologized hospital. *Sociology of Health and Illness*, 4,3 (1982), 255-278.

[18] Strauss, A. *Continual permutations of action*, Aldine Transaction, Chicago, IL, 1993.

[19] Tixier, M., Gaglio, G., and Lewkowicz, M. Translating social support practices into online services for family caregivers. In *Proc. GROUP 2009*, 71-80.

[20] Toscos, T., Connelly, K., and Rogers, Y. Best intentions: Health monitoring technology and children. In *Proc. CHI' 12*, 1431-1440.

[21] Turner, V. Betwixt and between: The liminal period in Rites de Passage. In *Proc. of the American Ethnological Society, Symposium on New Approaches to the Study of Religion*, 1964, 4-20.

[22] Weiner, C.L, Fagerhaugh, S., Suczek, B., and Strauss, A. *Social organization of medical work*. Transaction Publishers, New Brunswick, NJ, 1997.

[23] Yamashita, N., Kuzuoka, H., Hirata, K., and Kudo, T. Understanding the conflicting demands of family caregivers caring for depressed family members. In *Proc. CHI'13,* 2637-2646.