
Information Fragmentation and Continuity of Care in Bone Marrow Transplant

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Abstract

In managing chronic illness healthcare transcends the boundaries of clinical settings. Forming a holistic view of the patient's condition requires complex and integrated information work by patients, caregivers, and clinicians over an extended period of time. However, relevant information often remains fragmented - dispersed among an assemblage of people, institutions and artifacts, in diverse forms. Connecting fragmented information within and between clinical and non-clinical practices requires an enhanced understanding of boundary work that occurs at the junctures of these practices. Our work examines these issues in the context of bone marrow transplant.

Author Keywords

Information management; chronic illness; continuity of care; temporality; boundary objects

ACM Classification Keywords

H.1.2 User/Machine Systems, human factors

Introduction

Chronic illness places a heavy physical and psychosocial burden on the patient and caregivers, and carries weighty financial consequences for individuals, families, and health systems at large. Our work seeks to examine the information practices and challenges of a

complex specialty domain, bone marrow transplant (BMT); a tough and prolonged treatment option used for a number of chronic illnesses.

When facing chronic illness, healthcare transcends the boundaries of clinical settings. Patients must assume many responsibilities, such as tracking their own health data, practicing effective self-care, and managing symptoms. At the same time, management of chronic illness within clinical settings often involves coordinated care by multiple practitioners, and practitioners with different roles in the health system. The case is no different in the BMT domain.

The consequence is two major, and related, challenges to effective healthcare. First, complex and integrated information work is required by patients, caregivers, and clinicians alike, in order to facilitate a holistic view of the patient's condition, progress, and overall quality of life. This is complicated however, as relevant information often remains fragmented - dispersed among assemblages of people, institutions, and artifacts. As such, the care process is not only heavily dependent on effective information management and use in both clinical and non-clinical practices, but there is also an urgent need to develop ways of connecting fragmented information within and between these boundaries to ensure continuity of care over time.

Second, the chronic illness occurs over an extended period of time, and part of the information fragmentation problem is related to the temporal structure of disease progress and management. For example, how the illness progresses determines who gets involved in the care process, where, and in what ways (both in clinical and non-clinical settings). The

institutions that partly shape the illness experience have their own imbedded rhythms. And where in the illness trajectory the patient is might influence his or her own information practices [1]. Therefore, temporality likely plays particular and multiple roles in the management of chronic illness and associated information work. Yet we still have limited knowledge of what these are and how they influence the care process.

Bone Marrow Transplant

BMT is a non-surgical procedure used in the treatment of certain cancers, blood disorders, and immune deficiency disorders, whereby damaged or destroyed stem cells (which are responsible for making blood cells) are replaced with healthy ones harvested from the patient or a donor. Due to potentially serious complications that can manifest in multiple organs and the severity of the disease for which transplant is done in the first place, the physical and psychosocial burden of illness and treatment is heavy for BMT recipients. The care process is correspondingly complex for both patients and healthcare practitioners.

The nature of BMT necessitates that clinical oversight be foregrounded. Different specialists often get involved depending on how the transplant unfolds. Yet, as in other chronic conditions, BMT also requires the active participation of the patient as an absolutely critical element of the care process. The information work done by the patient is closely intertwined with the work done by clinicians. Patients need to learn how to recognize, monitor and report any telltale symptoms or incidents (which might indicate complications) in a timely manner, keep on top of their many medications,

and inform clinicians of relevant personal circumstances to fill important information gaps.

As expected, the role of the patient in care becomes more pronounced once he or she is discharged from the hospital following transplant, and continues long-term treatment as outpatient. Following initial discharge, intermittent complications may disrupt and alter the temporal course of progress and health management, and may even require readmission to the hospital.

The goal of our study is to investigate: (1) BMT patients' and clinicians' practices with regards to how they manage and use health-related information, and what implications these practices have for 'boundary work' (defined below for the context of this research) and continuity of care over time, and (2) the ways in which temporality plays part in information management and use practices within the BMT care process.

From an information viewpoint, understanding how assemblages – of people, institutions, artifacts – come together to manage information (and fail at it) is critical. We need to examine the ways in which illness information is fragmented and how it is connected in everyday practice. In order to do this effectively, we need to pay particular attention to the nature of boundary work. Following the ideas of Star and Griesemer [2], we consider boundary work as information work that occurs at the junctures of clinical and non-clinical practices. We believe that understanding prevailing information management and information flow practices in BMT clinical and non-clinical contexts helps us identify where and when boundary work occurs. In relation to these, we examine

why information may get lost or isolated, and where and when breakdowns in information management and use occur. We also examine how temporality influences information fragmentation and boundary work.

One broadly established mechanism to support boundary work is the use of boundary objects, defined as "objects which both inhabit several intersecting social worlds and satisfy the informational requirements of each of them" [2, p.393]. Between clinical and non-clinical practices there can exist many different boundary objects, or the potential for their use. Hospital discharge summaries, for example, are important boundary objects between clinical and non-clinical, as well as different clinical settings. They are also plagued with problems, such as audience issues (e.g. are they written for patients or other clinicians?) and what information to include.

Future analysis will determine how boundary work and boundary objects embedded in BMT clinical and non-clinical practices enable (or, alternatively, do not support) connecting the "information dots."

Methods

In order to study these issues, we employ interpretivist research methods. At the time this paper is being written, the first author has done over 50 hours of pre-study observations at two different BMT wards and at an outpatient BMT clinic located in the same research hospital. For these observations she shadowed a BMT clinical practitioner (a physician) in daily ward and outpatient activities. The goal of these pre-study observations was to introduce us to the everyday work and challenges for clinicians and patients in this specific domain.

To give an example of what we have seen, Susie (a composite persona, for privacy reasons) was diagnosed with AML, a kind of leukemia, at 29. Following “conditioning” therapy, which involved high doses of chemotherapy and radiation therapy to wipe out cancer cells from her bone marrow, she received transplant from an unknown donor (known as a ‘matched unrelated transplant’) 3 months after her initial diagnosis. Within 2 months following her transplant she experienced a mild skin rash, considerable weight loss, and was treated for infection that manifested in a fever. Although she was followed as outpatient at 4 months post-transplant, she had persistent lower back pain, found walking difficult, and showed symptoms of depression. She was on several medications to address her various ailments.

During the course of Susie’s illness and treatment, oncologists, BMT specialists, a dermatologist, an infectious disease specialist, physical therapists, a psychologist, and her primary care physician, among others, became involved in her care. Susie needed social support (provided largely by her sister), had to work closely with her insurance provider, coordinated part of her care, and strived to deal with daily activities.

The information work required to form a comprehensive picture of Susie’s case over time, and to meet her own, her clinicians’, and her sister’s needs and goals were immense. Yet bridging all of the necessary information

is essential for her treatment to move forward effectively.

Conclusion

Our work moving forward will employ ethnographically informed methods to examine the challenges and goals described in this paper within the BMT context. Our goal is to conduct observations at an outpatient BMT clinic over a period of months, observations at BMT support group meetings, and interviews with patients and clinical staff. We aim to have multiple interviews with patients that are separated across time by a few weeks or months. We also plan to examine artifacts in the BMT clinic and the information management tools and techniques used by patients. In so doing, we will necessarily move along the various boundaries and interactions among clinical, non-clinical, and patient practices.

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