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# The enactment of patient education for complex inpatients over the course of a stay in an interprofessional internal medicine inpatient unit

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# Abstract

This study seeks to provide insights on how patient education (PE) is enacted in an inpatient Internal Medicine Inpatient Unit at an academic teaching hospital in Ontario, Canada that has adopted Patient Oriented Discharge Summaries (PODS). A constructivist grounded theory methodology was conducted for 106 participant observations and 25 field interviews. We found that (1) patient education was not a single event but occurred at multiple *moments* throughout the course of care, and many components were required for PE to be effective (2) In addition to needing everyone in the same room, there needed to be an alignment of goals and concerns between the health care providers (HCPs), patients (Pts) and family advocates (FAs) (3) Team logistics and schedules meant that the same category of HCPs were present but not the individuals themselves (4) Though PODS functioned poorly as a boundary object, we found other documents/people who played the role of boundary. This study identifies a host of features that need to be attended to for effective re-engineering of inpatient PE throughout a hospital stay. Designing a better system for PE in the IMIU requires addressing all the levels of complexity as the current re-engineered discharge tools do not adequately address the barriers to having a PE conversation at the point of discharge.

## Keywords

# Summary for Lay Audience

The internal medicine inpatient unit (IMIU) cares for patients who are experiencing multiple health conditions at the same time. There are many health care providers (HCPs) involved in the care of these patients. With multiple moving parts to this setting, this study seeks to provide insights on how patient education (PE) is enacted in an IMIU at an academic teaching hospital in Ontario, Canada that has adopted Patient Oriented Discharge Summaries (PODS). The PODS is a quality improvement initiative delivered by the HCPs and provides patients with an easy to understand summary of instructions upon discharge. In order to understand how patient education happened in this setting, the researcher used direct observations and field interviews. In total, there was 106 participant observations and 25 field interviews conducted. We found that (1) patient education was not a single event but occurred at multiple *moments* throughout the course of care, and many components were required for PE to be effective (2) In addition to needing everyone in the same room, there needed to be an alignment of goals and concerns between the health care providers (HCPs), patients (Pts) and family advocates (FAs) for effective PE encounters (3) Team logistics and schedules meant that the same category of HCPs were present but not the individuals themselves (4) Though PODS wasn't an effective discharge tool in relation to PE, we identified other documents/people who were able to contribute to the underlying principles of PODS. This study identifies many features that need to be attended to for effective PE to happen throughout a patient's stay. Designing a better system for PE in the IMIU requires addressing all the levels of complexity as the current discharge tools do not adequately address the barriers to having a PE conversation at the point of discharge.

# Co-Authorship Statement

Talia Di Marco completed this work under the supervision of Dr. Mark Goldszmidt and Dr. Pamela McKenzie, who will be co-authors on the publication produced from this work. Dr. Mark Goldszmidt is an experienced internist with expertise in medical education and constructivist grounded theory methodology. Dr. Pamela McKenzie is PhD with a research area focused in library and information science, with expertise in constructivist grounded theory methodology. Talia Di Marco is a health information science master's student candidate who brought a fresh perspective having been naïve to the clinical environment previously.

Talia Di Marco conducted the data collection process and wrote the article drafts. These drafts were sent back and forth with Dr. McKenzie and Dr. Goldszmidt who provided multiple suggestions in editing the article and contributed in the data analysis.

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# Chapter 1

# 1    Introduction

Patient education is an essential component in modern health care (Leino-Kilpi et al., 2005). To date, however, patient education has largely been studied from the perspective of single encounters and single-system diseases such as surgical orthopaedic procedures (Giraudet-Le Quintrec et al., 2003). Largely ignored has been what happens in more complex inpatient settings such as internal medicine, where patients struggle with multi-comorbidities and where education needs to happen with multiple team members in an interprofessional context. As a result, there is a gap in our understanding in this context on how to create effective educational systems. This is a context that increasingly needs to be attended to with an aging population. Failing to do so has negative consequences for patient health. Research has confirmed the clinical value of patient education that meets health information needs (e.g., Osborne et al., 2007), and has shown that unmet patient information needs have been associated with a higher non-adherence rate to medications and treatments, readmission visits and medical errors (Pappa et al., 2013), particularly at the transition from hospital to home (Wang et al., 2017). It is therefore important to unpack why inpatient internal medicine has such increased complexity.

Firstly, it is essential to recognize that the complexity of effective health information mediation increases in settings such as internal medicine, where patients with multi-comorbidities generate complex challenges for clinical care (Fortin et al., 2006). Internal medicine patients, who represent 25% of hospital admissions, are typically older and the majority suffer from at least three chronic medical conditions (Vogeli et al., 2007). Quality of care for complex patients is influenced by the number of conditions as well as by "characteristics of specific conditions that reduce the amount of time or attention that are available for other issues" (Zulman et al., 2014, p.531). To date however, education practices for hospitalized patients have largely focused on simple problems, and educational tools have tried to take these simple ideas and apply these to complex environments, with limited success (Grossman et al., 2009).

People engaging with the health system as patients may seek information from beyond clinical sources, e.g., "from a combination of personal (e.g., self, friends, family) and impersonal (e.g., book, Internet) sources" (Lambert & Loiselle, 2007, p. 1013). The complexity in the internal medicine unit may be heightened by the presence of family advocates who want to play an active role in the patient's treatment plans and seek information regarding the hospital stay. According to Petronio et al., (2004), when family advocates were present, "information seeking was directed away from the patient and more toward the advocate," and "patients positioned responsibility on the advocate to assist them in the decision-making about their health issues" (p.33). The presence of advocates therefore has the potential to improve or to compromise effective patient education.

Finally, the interprofessional internal medicine team involves multiple health care providers in patient education over the course of the patient's stay. Patient education may be further complicated when multiple voices with different perspectives and addressing different problems are potentially each giving information at different times. Patient education is therefore not a one-time event, but rather a process that varies depending on "such contextual factors as professional role, the presence of information and communication technologies, and various sociotechnical configurations" (Wathen et al., 2008, p.182).

For my thesis, I studied the process of patient education in an internal medicine inpatient unit (IMIU) [1] characterized by complex patients; an interprofessional care team; the involvement of patients and other support people; patient education as being an *ongoing process* rather than an single event; and sociotechnical interrelationships among people and tools. Enabling people to make sense of the complex information being presented to

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[1] In Canada these are referred to as clinical teaching units (CTUs), however since this thesis includes an article written for an international journal that uses the term internal medicine inpatient unit (IMIU), I have used this term throughout the entire thesis. See Appendix A for a list of acronyms.

them is a key goal of Health Information Science (HIS). In order to achieve this goal in the IMIU setting, we must first understand the multiple moving parts of the education process. To date, there is little understanding of how health information seeking takes place when patient complexity is high, health care teams are diverse and complex, and family members may be involved.

In this integrated article thesis, I describe a Health Information Science approach in relation to the complex IMIU context, to examine what is known and what is yet to be discovered about the process of patient education. First, I review the literature and identify gaps in existing scholarship. Then I describe my Constructivist Grounded Theory (Charmaz, 2014) study design and methodology and outline the remainder of the thesis.

## 1.1 Literature review

To understand both the research methodology and why the IMIU is such a complex context it is important to review fundamental relevant literatures. In this section, I outline several important limitations in the literature on patient education within an inpatient setting. First, the research does not focus on patient education in complex settings for complex patients. Second, little attention has been given to the patient education in an interprofessional context. Third, the scholarship is overarchingly health care provider centric. Fourth, the literature assumes that patient education takes place at a single point in time. Lastly, the literature rarely considers the sociotechnical interrelationships among people and tools (Jensen & Kushniruk (2016); Keshet et al., 2013).

### 1.1.1 Complex patient

There is a great deal of literature that conceptualizes patient education and the role it plays for hospitalized patients. The focus of this type of research, however, is within a single system-based hospital admission where there is a very clear understanding of the things patients need to know (Oliver et al., 2001; Zangi et al., 2015). The literature on perioperative education is a prime example of this. This literature has recognized that there are important ways to give information; for example, through verbal instruction, leaflets or videos (Giraudet-Le Quintrec et al., 2003), and recognizes that pre-surgical

information reduced patient's anxiety and post-operative recovery (Bondy et al., 1999; Klafta & Roizen 1996). Johansson et al. (2002) found that surgical floor patients often require information on their disease(s), treatment(s) and medication(s), symptoms and complications (Johansson et al., 2002), the prevention of complications, and enhancing quality of life (Galloway & Graydon, 1996). What this literature does not do however, is address anything other than these single system issues. The literature presumes a linear, single system, and offers relatively straightforward strategies to adhere to patient's information and educational needs. What has not been addressed is how this education takes place with complex patients who have multiple comorbidities such as those admitted to the IMIU.

## 1.1.2 Interprofessional teams

The literature on health care provider/patient communication emphasizes interactions between single health care providers and single patients and does not reflect the nature of patient education in an interprofessional team environment (Giraudet-Le Quintrec et al., 2003; Zangi et al., 2015). To some extent, research has explored the concept of "teamwork" (Greysen et al., 2012; Wong et al., 2011), specifically around the discharge process, but " there has been less critical examination of the complex range of factors that affect the ways in which healthcare professionals work together (e.g. interprofessional friction, role boundaries, miscommunication, poor coordination of care) in General Internal medicine (GIM) from the perspective of the various healthcare professional" (Goldman et al., 2015, p.1454).

Patient education in IMIUs has multiple moving parts. Multiple team members are involved in the patient's care, and they may have different levels of sophistication of the understanding of the patient's condition(s). All team members have understandings and expertise consistent with their professional scope of practice, and although the attending physicians and senior residents focus on the overall clinical picture, the other team members may have important information about other pieces of the patient's condition. There is little dedicated time for explicitly discussing patient education within the interdisciplinary care team, so practice may be variable. In order to move forward in supporting better patient education over the course of a hospital stay, we need to

understand the educational components and the extent to which those are being taken up by the patients and their families. The challenge with patient education is to create possibilities for participation and collaboration across a diversity of sites both within and across the medical institution (Akkerman, Admiraal, & Simons, in press; Daniels, Edwards, Engestrom, Gallagher, & Ludvigsen, 2010; Ludvigsen, Lund, Rasmussen, & Saljo, 2010).

Different health care professions may also have different understandings of what patient education means. From a nursing perspective, the goal of patient education is not only for the patient to understand their current health status, but also to be able to make adequate and appropriate health care decisions or make necessary changes in order to arrive to an optimal state of health (Stephens et al., 2019). Patient education in physiotherapy seeks to "influence patients' knowledge and health behaviour," and "effective treatment and prevention require that patients gain understanding, skills and commitment" (Jason, 1997, p.178). Practicing pharmacists have not been traditionally involved in "patient education" per se, rather they follow "patient counseling guidelines which highlight the pharmacist's and pharmacy technician's responsibility in ensuring the safe and effective use of medicines by consumers" (Blom, & Krass, 2011, p.285). Different heath care professions may disagree on their respective roles in patient education. Auyeng et al. (2011) found that physicians and nurses believed that responsibility for informing patients about the action and usage of medicines was theirs alone while pharmacists viewed it as a shared responsibility, whereas doctors and nurses saw the task of informing patients on potential problems as a shared responsibility with pharmacists, while pharmacists considered it their responsibility alone. To date, much of the patient education literature does not dive into the varying roles and understandings of patient education across different health disciplines that are involved in an interprofessional IMIU team.

## 1.1.3 Health care provider focus

Initially focused on knowledge, skills, and attitudes, patient education has expanded to encompass concepts such as "empowerment, involvement, engagement, self-management, preferences, advocacy, partnership, health promotion, health literacy,

information and communication of/and/with/for the patients" (Lee &Garvin, 2003, p.449). Some patient education researchers acknowledge that "we must educate not merely for competence, but for capability (the ability to adapt to change, generate new knowledge, and continuously improve performance)" (Fraser & Greenhalgh, 2001, p.799). However, the scholarly literature tends to take a clinician-centered view on what information patients ought to want or need (Graydon et al., 1997; Galloway & Graydon, 1996). For example, many studies aiming to address patient learner needs will use a Patient Learning Needs Scale (PLNS) or questionnaires to report on specific learner/ information needs. While this may provide the researchers with a general idea of what is important to patients, the findings are ultimately driven by the clinician's perspective, as the clinicians generate the topics from which the patients choose to represent their educational needs. This health care provider perspective is evident throughout much of the literature; for example, physicians in Fairmont County consider effective patient education to consist of merely telling patients what to do or tell them about health issues "[We need] more emphasis on preventive care and more education, more general education…just flat telling people, educating people that this is needed and that there's problems that can be cured if you catch them early that can't be cured if you don't.'' (Lee & Garvin, 2003, p. 454).

According to Lee & Garvin (2003), the literature assumes that simply providing information is sufficient to produce improved health outcomes in individuals and populations. However, not all patients want the responsibility of being in control of their health care (Salmon and Hall, 2004). With little evidence demonstrating that "empowered" patients take better care of their health, Rodmell and Watt (1986) argue that there is a failure to recognise the limitations of the concept of consumer "choice" in health. They argue that "the giving of knowledge by professionals to clients is not enough in itself to facilitate choice" and that "the making of a 'free choice' does not necessarily equate with a 'healthy choice' and nor does this necessarily equate with 'health'" (p.6). and that health communication practices and frameworks are "largely based on the assumption that changes in individual knowledge, attitudes, and beliefs will translate into changes in behaviour" (p.7). This presumption implies that the flow of information from the creator to the user is unidirectional and linear, making the information transfer more

of a monologue rather than a discussion (Lee & Garvin, 2003). This hierarchical, one-sided relationship assumed by many health communications practices limits knowledge users' ability to address what information is actually necessary to them. For example, when the physician determines what information is relevant, this defines the limitations and boundaries of the discussion between them and the patient. This also controls the participation (or lack thereof) of the patient, forms a diagnosis, and defines the treatment (Lee & Garvin, 2003). By critically examining health communication in various practices, the authors recommend a move from "information transfer to information exchange" as a new approach to understand health communication practices. They caution that this suggested approach will not be an overnight success but note that changes are starting to be implemented into practice in order to move towards a broader view of what constitutes health, and in particular frequently constitutes a proactive and bidirectional approach (Lee & Garvin 2003; Truccolo, 2016).

It is important to note that within an inpatient internal medicine IMIU, not all patients are health information seekers as they are not all active patients. These patients may not be "seeking" anything, and simply want to be cared for. The issue is that once the need to be cared for is over, health information is still required in order to transition back to their respective homes, and necessary in order to continue their ongoing health care journey. Within the context of this study, it is possible that patients may chose to ignore this health information and yet we know with certainty that failing to be educated about the illness(es) and post-discharge protocols can lead to negative outcomes (Pappa et al., 2013). However, many patient education models assume a "consumerist patient" making them health care provider centric, presuming that we know what patients' needs are and that they will act as active seekers of that information. In the internal medicine context, neither of these assumptions is necessarily true. Therefore, a shift in focus may lead us to ask the question of what is relevant and salient to each patient and how information is provided in ways that is accessible in the moment and when they leave. In order to address this gap, we must be reminded of one of the goals of health information science research, which is to identify ways to empower health information "seekers" at various levels of engagement.

## 1.1.4 Patient education as a single moment in time

A large number of studies on patient education in hospital settings focus on a single event. Tools such as the Patient Learning Needs Scale (PLNS) are designed to understand patients' perceived learning needs at a specific point in time. This approach ignores the fact that new information needs may develop throughout a patient's stay.

The point of hospital discharge has been studied as a time when health care providers can somehow convey all the key bits that the patients would need both from their and the health care provider's perspective (Borgsteede et al., 2011; Knier et al., 2015). The small body of research that does centre around PE for the complex internal medicine patient has focused on the point of hospital discharge (Pinelli, V., et al., 2017). A recent Canadian study of discharge education in an IMIU found that "the organization of clinical work in combination with clinical teaching influenced interprofessional interactions and the quality of discharge in this GIM [general internal medicine] unit" (Goldman et al., 2015). This study reinforces the point made by Dennis et al (2014) that there is a need for ongoing attention to the balance between medical education and patient care, "a topic identified as an area of priority in medical education research" (p.1080). In order to address this balance, Goldman et al. (2015) provide strategies such as including "further attention to education about discharge and alternative interprofessional approaches for discharge, particularly given the turnover of medical attendings and residents." (p.1456) A follow up study conducted by Goldman et al (2016), elaborated on these findings and focused on the interprofessional collaboration related to discharge in a general internal medicine unit. This study unpacked the social factors and processes involved in interprofessional interactions in discharge and showed that organizational tensions challenge an interprofessional approach and that medical dominance shaped discharge practices in the IMIU (Goldman et al., 2016). Interestingly, both of these studies highlight the importance and the complexity of the discharge process within an IMIU, ensuring "a safe and high-quality patient discharge experience and reducing unnecessary readmissions" (Goldman et al., 2016). Though these studies have given a glimpse at potential balancing strategies to improve the interprofessional discharge process, the

patient education strategy is still considered to be a single event which is emphasized at the time of discharge.

Discharge has likewise become the target of hospital-wide quality improvement initiatives with the goal of reducing IMIU readmissions. Evidence-based discharge education models such as the Re-Engineered Discharge Process (RED) have been a part of this move (Jack et al., 2013). The Re-engineered Discharge process was created by researchers at Boston Medical Center, aims to reduce readmissions. RED prioritizes a comprehensive discharge process that properly prepares patients for the transition from hospital to home. The Agency for Healthcare Research and Quality (AHRQ) developed a toolkit to assist in applying the process in hospital discharges. The Re-engineered Discharge Process consists of "a set of 12 mutually reinforcing actions […] that the hospital undertakes during and after the hospital stay to ensure a smooth and effective transition at discharge". While improving the discharge process is clearly important, this thesis shows that the point of discharge on its own does not fully capture the PE needs in an IMIU setting.

## 1.1.5 Sociotechnical interrelationships

Literature also tends to focus either on interpersonal communication or on the roles of patient education materials, but rarely considers the sociotechnical interrelationships among people and tools (Jensen & Kushniruk (2016); Keshet et al., 2013). Two concepts are particularly salient here: the notion of a boundary object and the concepts of *infomediation* and *info(r)mediation*.

> Star & Griesemer (1989) define boundary objects as objects that
>
> "both inhabit several intersecting worlds and satisfy the informational requirements of each of them. . . . [They are] both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use, and become strongly structured in individual site use" (Star & Griesemer, 1989, p. 393)

The purpose of a boundary object (BO) is to enable different groups to work together within "a situation of multi-site work relations and requirements" (Star & Griesemer, 1989, p. 393) such as an internal medicine unit. Boundary objects can serve as a means of enabling communication and collaboration across sites. According to Huvila et al (2017) "the concept of the BO makes visible the sociotechnical contexts within which people seek, retrieve, use, share, and curate information" (p.1807). Artifacts can fail as boundary objects when "they do not fully or rightfully capture multiple meanings and perspective" (Akkerman and Bakker, 201, p.141).

Hasu and Engeström (2000) demonstrated that "supportive message boxes with system-related information about a medical technology were designed by system designers but failed to be supportive because the concerns and interpretations of users were not accounted for". In addition, boundary objects may be perceived and utilized differently by health care professionals and patients, and this can lead to the boundary objects losing their boundary crossing functions over time (Barrett & Oborn, 2010; Pennington, 2010). From a health information science research lens, many central concepts and tools such as knowledge organization, information systems, and documents can be fruitfully conceptualized as boundary objects. According to Huvila et al (2017) "Thinking about the concept can make us more sensitive to how individuals, communities, and things interact on the levels of artifacts, practices, and their epistemic premises, and how these interactions have implications for their respective positions in mutual context" (p.1812).

Wathen et al (2008) identify two processes through which health information may be mediated: *infomediation* is the inevitable transformation that occurs when a piece of information is exchanged from one person or situation to another. *Info(r)mediation* conceptualizes the situations in which "a human mediator conveys information in order to effect change in the behaviour or actions of those looking for information" (Wathen et al., 2008, p.6). In other words, infomediators change the information in some way, which cannot be avoided, and the mechanism of change may be unclear. *Info(r)mediation* recognizes the inevitable transformation and tries to influence or manipulate how this information gets taken up. As a form of info(r)mediary work, patient education is not "neutral provision of information to patients" (Wathen et al., 2008, p.18). Health

information seeking and mediating processes are complex in nature as they require intensive time and resources allocated to their development (Wathen et al., 2008; Harris et al., 2010).

Therefore, the concept of a boundary object supports this thesis, and concept of *infomediation* helps to explain the ways that objects, documents, and people achieve boundary object status. *Info(r)mediation* recognizes that regardless of the effect of humans or objects, or a mix of the two, we need to be more deliberative in trying to scale boundary objects so they can more consistently achieve the outcome of understanding in change that is intended through the education process.

## 1.1.6 Literature review gap summary

Together, these five gaps mean that little is known about patient education for complex patients through the course of the inpatient stay in internal medicine IMIUs. Without research and guidance that reflect this complexity, inpatient services that provide care to such patient populations are left to develop strategies on their own without sufficient robust guidance from theory. More specifically, there is a lack of alignment between what the theory developed by the health information science field says, and how the literature of patient education has been documented and conceptualized. The current literature demonstrates that we do not fully understand patient education as a phenomenon and my study explored these gaps in relation to this context, to gain insight of its overarching enactment.

## 1.2    Research questions

I studied how PE is enacted in an inpatient IMIU at an academic teaching hospital in Ontario. I asked the following overarching question with three sub-questions:

*How is patient education enacted in an inpatient internal medicine setting in a teaching hospital?*

   o   *How do various health care professionals interact with one another, with the patient, and with family advocates?*

- o *Are there documents or objects that function as boundary objects in support of patient education?*
- o *When does patient education happen?*

## 1.3 Methodology

### 1.3.1 Paradigm position

This study was rooted in a constructivist paradigmatic lens, which focused on understanding the overarching enactment of patient education in an internal medicine unit. The participants co-constructed the findings of this study as their subjective understanding of patient education experiences and moments enabled me to gain a deeper insight into their interpretations (Charmaz, 2014). This subjective approach allowed me to better elicit and understand how the research participants constructed their own individual and shared meanings around patient education. It must be noted that I also recognize that my own interpretations, as well as those of the participants, have influenced the data collection and analysis process. By acknowledging the co-construction of my own interpretations and those of the participants, I made sure to conduct research in a reflexive and transparent manner. According to Finlay (2006), reflexivity is to be integrated throughout the research process and acts as "thoughtful, conscious self-awareness" (p.532) of subjective responses, intersubjective dynamics, and research process. Throughout this entire research project, the best way for me to understand how to practice reflexivity came from Suzuki, Ahluwalia, Aurora, & Mattis (2007) who state that "…we [as researchers] are neither cameras, passively capturing a snapshot of the social landscape, nor mirrors, reflecting back an objective reality. Instead, we are active agents seeking to learn about the world through each piece of data we collect" (p.290). For this reason, I made sure to articulate my assumptions and experiences through reflexive and analytical memos during the data collection and analysis process. I would then discuss the content of these during meetings with my supervisors which further allowed me to query and challenge these assumptions and emerging understandings of education practice.

## 1.3.2 CGT methodology

Working within a constructivist paradigm, I chose a constructivist grounded theory (CGT) methodology to conduct this qualitative research project. There are varying types of grounded theory methodologies and it is important to acknowledge some of the fundamental differences between the original grounded theory methodology (Glaser and Strauss, 1967) and my chosen constructivist grounded theory methodology (Charmaz, 2014). Classical grounded theory philosophically aligns with a positivist paradigm (Glaser and Strauss,1967) compared to constructivist grounded theory which allows for interpretive understandings and iterative logic (Charmaz, 2014). With regards to data collection and analysis, classical grounded theory suggests that no prior knowledge should influence a research study, or its data collected (Glaser and Strauss, 1967), whereas, constructivist grounded theory emphasizes that prior knowledge and a researcher's experience can become significant within a research study (Charmaz, 2014).

Constructivist grounded theory (CGT) can be described as being ontologically relativist and epistemologically subjectivist, where the first indicates that we accept facts that are real independently of the human mind. The second implies that the standards of rational belief are those of the individual believer. This position assumes that "neither data nor theories are discovered, but researchers construct them as a result of their interactions with their participants and emerging analyses" (Charmaz, 2006; 2009; Thornberg and Charmaz, 2012). This enables me to contextualize and gain an in-depth insight into the specific concept of the patient education phenomenon. CGT methodology is well suited to my goal of understanding and exploring a social phenomenon.

A CGT keeps the researcher close to participants as they are active in the co-construction of knowledge (Charmaz, 2014). This methodology emphasizes a mutual creation of knowledge and claims to interpret a reality contributed by both the researcher and the informants. CGT explicitly incorporates reflexivity as it "must take the researcher's position, perspective, and interaction into account as an inherent part of the research process" (Charmaz, 2014, p.13). CGT methods provide the researcher with the ability to shape and reshape data collection in order to refine the data collected. The initial interests and questions underlying the research are refined over time as data collection and

analysis occur simultaneously, and the researcher constructs theory as an outcome of their interpretation of the participant's story (Seidel & Urquheart, 2016). This continual refinement allows the researcher to gain and increase their knowledge when addressing such complex social phenomena. In other words, the researcher learns things along the way to reshape the questions being asked to more accurately shape the data collection and emphasize the analysis. CGT methods aim to develop conceptual categories. The general CGT strategy is as follows: first we aim to seek the data, describe the observed events, answer fundamental questions about what is happening and develop theoretical categories to understand it.

## 1.3.3 Role of the researcher

Consistent with a constructivist grounded theory methodology, I acknowledge that my own experiences and assumptions influenced this research project. In order to balance the influence that my own interpretations would have had on the findings, I made sure I continuously wrote memos in order to acknowledge my position and perspective as there is a need for self-awareness and critical reflection on self and context.

Growing up in Sudbury Ontario, I quickly realized there were many barriers to receiving health care in a small town in Northern Ontario. For this reason, I pursed an education in health promotion and volunteered in community-based health centres, working with many vulnerable/minority groups. I myself have also been subject to many clinical visits, where I did not receive the most optimal care and often left the visit more confused, as my particular questions were never properly answered. With these experiences, I learned and listened and became aware of the many fundamental components in health care that were lacking or that needed more focus. In addition to this, I have been pursuing a career in medicine and having such a mindset enabled me to observe with the sensibility of a patient and an aspiring physician. Hence, I was extremely motivated and in an excellent position to observe what was happening from both the health care provider and patient perspectives. Therefore, my interest in exploring patient education in a clinical setting has been reinforced by my many personal experiences and my academic career.

I believe that as a master's student I was able to bring a fresh perspective having been naïve to the clinical inpatient environment previously. This enabled me to immerse myself in the clinical environment and to gain a conceptual understanding of the multiple components that make up this setting. This being said, my experiences have shaped the way I designed and framed interview questions, the way in which I probed these participants. They have also influenced my interpretation of the findings I reported. Throughout the iterative process of data collection and analysis, I came to recognize that every person involved in this research brought their own perspective, and that I actively interpreted these multiple perspectives to make sense of these findings.

## 1.3.4 The research setting

The study was conducted in the internal medicine unit in an academic teaching hospital. This hospital has three Clinical Teaching Unit (CTU) teams, multi-layered teams supervised by an attending physician. Each team has 2 senior medical residents; one second year and one third-year resident. The teams also have "4-8 junior trainees typical consisting of 2-4 senior medical students who are called clinical clerks and 2-4 first-year (junior) residents" (Goldszmidt, 2015, p. 11). This interdisciplinary team consists of many health care professionals, which include a social worker, a physiotherapist, an occupational therapist, a patient care facilitator, a pharmacist, a dietician, a home care coordinator, and bedside nurses. During the observations, I observed that the nurse-patient ratio is 1:4, with the same ratio typically being used for medical students assigned to patients. Depending on the team's daily census, the resident-to-patient ratio is anywhere from 1:5-1:8. Because there are three IMIU teams on the ward studied, nurses are split between teams such that any given nurse might be looking after 2 patients from 1 team and 1 patient from each of the other teams.

When a patient is admitted to the internal medicine unit, they are first greeted in the emergency department. From there, a health care provider transfers the patient to the appropriate floor. Most patients are admitted overnight, when one senior resident is on call, supported by one junior trainee (medical student or first year resident) from each team. The average length of a patient's stay in the internal medicine inpatient unit is 5 days. A typical day on the internal medicine ward may resemble the following schedule:

At 08.30h the senior resident(s) gather quickly for 10-15 minutes with the health care team in their team rooms. During these morning rounds, the patient care facilitator reviews the day's census to go over which patients can potentially go home within the next 24-48 hours. At this time, the team also discusses what resources may be needed to be put in place in order for a safe discharge and transition to home. After this, the senior resident and the patient care facilitator stays in the room while the remainder of the health care team exits. The physician team then gathers in their team room. The junior residents present overnight issues followed by patient cases and the assessment of the previous night's admissions. All members of the team then disperse and take care of the patients they are responsible for. At 13h00h, "bullet rounds" occur with the senior resident along with members of the interdisciplinary team. Once again, they quickly discuss all patients on the team with a focus on "which patients might go home within the next 24–48 hours and the resources that might be required to ensure they can be discharged safely…" (Goldszmidt, 2017). Throughout the day, the junior trainees and residents write daily progress notes and discharge summaries for their patients.

A typical day on the IMIU during the observation period saw 25-35 patients assigned to each team, and the number of admissions and discharges per day ranged from 2-8. The hospital prioritized discharging patients prior to 11 AM or, at the latest, 2 PM. In reality, I observed that discharge could take place at any time, and neither nurses nor other team members had time built into their schedules for conducting discharge education.

It is important to note that while several members of this interdisciplinary team are more constant, others are constantly changing. Every team has a roster of attending physicians that rotate every two weeks, a roster of residents who change every 4 weeks, and medical students who rotate every six weeks. Most of the health care providers work consistently from Monday to Friday (the physiotherapist, the occupational therapist, the patient care facilitator, the pharmacist, the home care coordinator, the social worker, and the registered dietician). The nurses have multiple and variable schedules, and a common pattern was three days and three nights. The nurses are not always assigned to the same team or patient for each day. Notably, "because of post-call absences and absences for trainee teaching or out of sequence rotation changes, the actual team membership is

highly variable, thus creating fragmented teams" (Goldszmidt, 2015, p. 13). This variation results in constantly shifting team composition over a 12-week overall cycle (see Table 1). With a constant shift in team members, there are numerous learners involved in this particular context. This puts a heavy burden on the IMIU team's ability to support collective care.

The IMIU studied in this thesis had recently introduced a new Re-engineered Discharge (RED)-based quality improvement process, Patient Oriented Discharge Summaries (PODS), for standardizing PE at discharge. At the time of observation, PODS had been implemented in the team's routines. PODS is an instrument developed collaboratively by health care providers and patients. Its implementation is supported by ARTIC (Adopting Research to Improve Care), a joint program of the Council of Academic Hospitals of Ontario and Health Quality Ontario. According to Health Quality Ontario, PODS *"provides patients with easy-to-understand instructions upon discharge that also facilitate a tailored and clear discussion between health care providers and patients on what the patient needs to know and do once they return home."* The instrument holds a patient's record and is accessible to heads of department and team members to facilitate the coordination of PE across the health care team. Whereas the Re-Engineered Discharge process assumes that a team will include a designated discharge educator, PODS does not. PODS is designed to be reviewed by the physician with the patient prior to discharge to summarize what happened during the hospital stay, explain what changes patients should expect after discharge, describe follow-up plans, flag medication changes, and identify who to contact if problems develop (Hahn-Goldberg et al., 2016).

PODS was designed to function as a boundary object (Star and Griesemer 1989) to support patient education across team members of the IMIU. It is important to note that both the PODS instrument and the scholarly literature are based on the assumption that there is a singular patient education event that takes place, that one instrument and one event will solve the problem of patient information gaps. However, in an interprofessional internal medicine setting, patient education is rarely confined to a single event.

## 1.3.5 Contextual factors

There are a few contextual factors that are important to address while studying an inpatient internal medicine IMIU. Firstly, according to Goldszmidt et al. (2015) p.59, "The attending physician has overall responsibility for inpatient care and supervises the physicians-in-training (residents and medical students) who help deliver that care in a teaching team setting". There can be a wide degree of variability in practices amongst attendings and how their roles are enacted. Interestingly Goldszmidt et al. (2015) identified four styles which take into account all three aspects of attending practice – patient care, trainee education, and team oversight. The four supervisory styles were identified as: "direct care, empowerment, mixed practice, and minimalist" Goldszmidt et al. (2015). Noticeably, these styles all varied in delegating patient care responsibility. With shifting team membership leadership every 2 weeks, there is never a constant attending physician. This leads to a variety of supervisory styles, which could have an impact on team competence, and professional development for both trainees and faculty working in these settings. Patient care responsibility may be shifted from physician team members throughout a patient's stay and could ultimately lead to varying levels of education being projected from attending to resident to patient.

A second important factor to consider is the geographical movement that takes place within hospital during a patient's stay. This refers to changes in the level, location, or providers of care as patients move within the health care system. In particular, an IMIU utilizes many locations which can be spread throughout the hospital. The within-hospital movement commences when preparing a patient to leave one setting and concludes when the patient is received in the next setting. This poses challenges that distinguishes it from other types of care as many IMIU transitions are unplanned. This could be a result of unanticipated medical problems, which is very likely when dealing with complex patients (Coleman & Berenson, 2004).

The setting and the context of this study are essential to understand in order to fully grasp the enactment of patient education within an IMIU setting. In this case, the PODS is a feature of the context as it seeks to serve as a shared boundary object across the multidisciplinary members, with the purpose of improving patient education at the time

of discharge. Within this setting, there are multiple people who are providing education at different times as there are multiple moving parts.

## 1.3.6 CGT observational study

My primary data collection methods included direct observations, which included field notes describing oral and written education and communication practices observed; as well as field interviews, which consisted of brief audio recorded field interview sessions. Combining both of these data collection methods provided me with a rich opportunity for understanding a social phenomenon. I believe that had I only conducted interviews; I would have never been able to gain the insight that arose from the observations. Throughout the study, I observed oral and written education and communication practices among health care providers of the IMIU teams and their patients/family advocates. These observations included attending morning and afternoon rounds on the IMIU. Attending rounds allowed me to identify specific health care providers to shadow and listening to the review of the day's patient census enabled me to purposefully select patients that were best suited to contribute to my research. In addition to the morning and afternoon rounds, I observed nursing handovers, oral communications accompanying the admission of new patients to the wards, discharge summary presentations, and health care provider interactions with other team members and patients and their families.

Conducting a constructivist grounded theory (CGT) field study where the primary data collection methods are direct observations and field interviews is not without its challenges. The IMIU is a very chaotic and busy ward, and the participants didn't always have time to explain what was going on. This meant that I had to spend more time in the field and choose my opportunities for key informants in order to provide some of those insights around context that I would not have been able to understand. In addition, because this study was designed as a CGT, the initial interview prompts were not "scripts" but rather offered questions to focus data collection that were revised in response to the context (see Appendix B for interview prompts). I interpreted this context based off of the observations that led me to the interview moments. For example, without observing the clinical interactions between health care providers and patients, I wouldn't have been able to take note of contextual factors or background information that was

happening prior to the interviews. Had I only used interviews as my primary data collection method, the insights gained would have been superficial.

## 1.3.7 Data collection

Data collection took place during 26 study days (127 field hours) over a 3-month period from September-November 2019. Most study days started at 8:00 am and ended around 2:00pm, with some evening, early morning and weekend observations. I observed interactions and written education and communication practices among health care providers and their patients. Initial sampling was purposive to maximize variation in times of day, days of the week, type of health care provider, ongoing team interactions versus new team member changeovers, and different schedules in relation to shifting team memberships. These purposeful sampling strategies were used as I wanted to ensure that the participants, I selected could meaningfully contribute to greater conceptual clarity associated with constructivist grounded theory and to ensure I achieve maximum variation. HIS theory helped inform me in relation to the process in particular, as it helps focus my attention across temporal times which lead to purposeful sampling.

After securing informed consent (see Appendix C-E), I collected data through non-participant observations and 25 field interviews that ranged from 10-45 minutes with patients, family advocates, health care providers, and physician team members. I observed each of the three teams that make up the IMIU and observed a total of 106 participants. Patient participants ranged in age from 19-99 years and were sampled broadly for age, gender, availability of family advocates and variety and complexity of clinical condition(s) (refer to Table 2 for participant breakdown).

As the study proceeded, I moved toward more theoretical sampling to test the developing findings and seek both confirmatory and negative cases. Data collection continued until theoretical sufficiency was reached, which did not mean that "no new ideas would have been identified with more data collection, rather we had achieved sufficient data collection to enable an understanding of the dimensions of interdependence" (Dey, 1999). Collected data included interview transcripts, field notes describing oral and written education practices observed on the IMIU, as well as clinical documentation used for

education purposes. Considering the intense direct observations and field interviews required for this study, an iterative process of data collection and analysis was ongoing throughout the three-month time period.

In the month prior to starting data collection, I was able to tag along with a research student who was conducting her own research in the IMIU. This was extremely beneficial for me as I was able to familiarize myself with the IMIU setting. At this time, I took notes on the physical environment, the logistics of how the IMIU ran during a typical day and what I thought would be helpful in my own study. During the first week of my data collection period, I listened and observed by taking general field notes in order to sensitize me to the setting. Following this, I collected data on various occasions. During direct observations, I aimed to observe key educational practices identified as important to patient care (e.g., nursing handovers, daily interdisciplinary 'bullet' rounds, oral communications accompanying the admission of new patients to the wards and discharge summary presentations, and health care provider interactions with other team members and patients). During the observation of these activities, I recorded standard, handwritten observational field notes. The field notes focused on describing education practices, educational challenges, workarounds, and shared and unshared knowledges possessed by different individuals in the setting. From my observations, I then conducted field interviews with health care professionals as well as with patients. The field interviews were conversations between the team member and me, which allowed for clarification of any questions that arose during observations and elucidation of tacit meaning or background information. The patient field interviews had the same purpose but were, in some cases, much longer, in depth conversations. I recorded particular field interviews with a LiveScribe pen that allowed me to quickly and unobtrusively go from making field notes to recording if a conversation became one, I wanted to record. Throughout the process of direct observations and field interviews, I also incorporated reflexive and analytical memos in my field notes. I did this as often as I thought necessary, in order to record my reflexive process. Clinical documentation was also collected, such as de-identified copies of relevant patient case files (e.g., progress notes, orders, and nursing charts). Data was additionally collected from patients to better understand their experience of being unwell and requiring care. Family advocates were also invited to

participate in the study. Interviews with patients and families took place throughout the patient's stay in hospital (as tolerated). The interview protocol was designed and developed through a CGT lens; therefore, it acted as an exemplary script. Changes to the specific questions occurred during the interview based off of the patient's responses, although the questions focused on developing the main purpose of the study. The CGT observational study gave priority to the studied phenomenon or the process – rather than the setting itself.

The study aimed to recruit approximately 20-30 patients, keeping in mind that I would not ever have the full picture of each patient, but rather see the overarching enactment by seeing the multiples. I observed these patients through an extended period of shadowing, where I shadowed an individual over several hours and on more than one occasion (9 patients), and brief observation periods that took place in the context of team rounds, and subsequent opportunities that arose as team members went to visit individual patients, or when observing small group interactions (34 patients). Through these data collection methods, I observed a total of 43 patients and collected 9 field interviews (refer to Table 2).

There are twenty-one health care providers, and at the hospital being studied, there are seven attached to each team. There is a roster of attending physicians, residents, and medical students who rotate ever 2-4-6 weeks. Therefore, across the three-month period, I expected to observe between 20 and 40 health care providers. Just as with the patient participants, I observed health care providers through both an extended period of shadowing (16 health care providers) and brief observation periods (28 health care providers) (refer to Table 2). Through these data collection methods, I observed a total of 44 health care providers and collected 14 field interviews from 2 nurses, 3 patient care facilitators, 1 home care worker, 1 social worker, 1 registered dietician, 2 medical students, and 4 residents.

I was also able to include family advocates in the participant group. I collected data from family advocates through both an extended period of shadowing (1 family advocate) and brief observation periods (17 family advocates). The availability of family advocates was

unpredictable. For example, when visiting 26 patients with the physician team on a weekday from 10am-3pm, only 7 advocates/caregivers were present. However, when observing 20 patients on the weekend, from 9am-4pm, 11 advocates/caregivers were present. This made it very difficult to target family advocates for an extended period of shadowing. However, throughout the study I was able to consent a total of 18 family advocates and I collected 2 field interviews.

## 1.3.8 Data analysis

### 1.3.8.1    Summary

I analyzed the data collected using a constructivist grounded theory (CGT) approach (Charmaz, 2014). CGT uses an inductive approach to analysis, where the patterns, themes, and categories of analysis are indicated by the data (Charmaz, 2014). I transcribed the interviews verbatim after each study day. Anonymized field notes and transcripts were stored on a password-protected computer and uploaded to Nvivo 12. Using the collated files, I analyzed and coded the data using CGT, with iterative phases of data collection and analysis and constant comparison (Charmaz, 2014). During the data collection period, I met with one or both of my co-supervisors bi-weekly for approximately two hours to discuss initial open coding and emerging and common themes. The analysis led me to identify gaps that drove theoretical sampling of subsequent recruitment in this study. Consistent with a CGT methodology, data analysis moved from initial open codes to a set of focused codes and finally towards theoretical coding (Charmaz, 2014). Data collection and analysis was an iterative process such that as new insights emerged, data collection and sampling strategies were modified. Additionally, a constant comparative approach was used so that new insights and codes were also applied to previously analyzed data. This process enabled the emergence of major analytical categories and subcategories that led to the abstract theoretical understanding of patient education in the studied context.

In this study, coding was not a linear process. Specifically, because of the nature of the research setting, I moved back and forth between the different phases of coding. For the most part, initial coding was completed at the beginning of the study. I moved through

the iterative data collection and analysis process, attending to both emergent themes and patterns resonant with relevant literature. Literature was used at every stage of this project in order to compile a literature review. This scholarship was used to clarify concepts, identify the area of focus, and to justify the research question.

## 1.3.8.2   Coding

The initial process of open coding helped identify some patterns in the data pertaining to participants and observation notes. Here, I looked for relationships between concepts found in the data. In this process, I identified distinguishable features between patients, and types of concerns each may have had. I also identified health care provider issues, some of which related to patient concerns and others that did not. Throughout the iteration of data collection and analysis, constant comparative processes were used to look closely at the data for possible connections between these identified categories (Thornberg & Charmaz, 2014). As data analysis continued, every few weeks I would come up with a list of things I knew that could contribute to the knowledge claims, and a list of gaps that still needed clarification. This let me to identify early connections in the data which enabled theoretical sampling for concepts within the data as it emerged.

Further along, I was able to identify issues that were at play that needed education, decision-making and planning. At this time, I came up with eight issues looking at both the health care provider and the patients' perspective. This open coding process enabled me to identify various pieces that health care teams educate patients on in hospital, which type of participants cared about these, and the variations and differences. After this coding process, I was able to find further connections between how these educational pieces play out in the IMIU setting. Additionally, I identified certain features from patients and families that either constrained or engaged them throughout the educational moments.

Moving toward a more focused coding process, I revisited the gaps that I had previously identified, and looked to the data to understand a particular aspect of them. At this time, I focused my research questions to gain a deeper understanding of the complexity

surrounding key processes in the data (Conlon et al., 2015). As a result of completing the initial coding, I was able to identify the most significant and frequent initial codes.

The focused coding guidelines offer a more sensitive and flexible approach to data analysis (Charmaz 2006). According to Thornberg and Charmaz (2012, p.48) "The constructivist position of grounded theory is more flexible by being open for more than one significant or frequent initial code in order to conduct this further work. Such openness also means that the researcher continues to determine the adequacy of those codes during the focused coding". During my monthly meetings with my supervisors, we explored and decided which emerging codes best captured what I saw was happening in the data. From there conceptual categories emerged in which I provided definitions and identified potential relationships between them (Charmaz, 2006). The integration of constant comparison enabled us to generate refined concepts. These concepts are what was needed in order to move from a purposeful to a theoretical sampling technique.

Consistent with constructivist grounded theory, my final stage of coding consisted of theoretical coding. According to Holton (2007, p.283) theoretical coding is "the identification and use of appropriate theoretical codes to achieve an integrated theoretical framework for the overall grounded theory". This involved theoretical integration of my concepts as I refined these and tried to demonstrate a relationship between them (Thornberg & Charmaz, 2014). The theoretical coding process consisted of ideas, abstract models and perspectives brought on by a range of lenses and theories from the research team. These preceding theoretical codes specified "possible relationships between categories developed in the focused coding … [and] may help tell an analytic story that has coherence" (Charmaz, 2006, p.63). The different theoretical lenses brought to this study arose as the research team members came from various disciplines. Coming from a health promotion background, I utilized the holistic health concepts I have learned when interpreting data in order to achieve a comprehensive understanding of the patient education moments that occurred.

## 1.3.8.3 Software used for analysis

I uploaded all transcripts, memos and direct observation notes into Nvivo 12. However, it was not until the later stages of focused and theoretical coding that I used the Nvivo 12 features to their full extent. The software was great for providing an organised and structured approach to analysis. All of the data can be found in one place and I was able to analyse across my various types of data formats utilising the same thematic structure. However, I did not complete line by line coding and as a first-time user of Nvivo 12, I found that the program was ultimately more of a data management tool. While providing a means to store, code and report data, the theoretical analysis and the emergence of major theoretical concepts really came from hand-written, visual notes. This constructivist grounded theory study required that I move back and forth between steps in analysis, refining and re-interpreting the data throughout the iterative process. In order to make sense of the compilation of various data sources, I believe it was necessary for me to engage with the analysis by generating hand-written thematic diagrams, tables and lists, which is not something Nvivo 12 is equipped to do. This was tedious work, but I believe that the combination of using both Nvivo 12 and hand-written based analysis was key to navigating through the iterative data collection and analysis process. They both offered valuable functions and enabled deep engagement with the data.

## 1.3.9 Quality considerations

Throughout this study, I used Tracy's (2010) "big tent" criteria to ensure the quality of the research. According to Tracy (2010), high quality qualitative methodological research is marked by eight criteria. For the purpose of this thesis, I will be focusing on the rich rigor, sincerity and credibility criteria and describe their importance in quality considerations in this constructivist grounded theory methodology.

## 1.3.9.1 Rich rigor

Tracy (2010) describes that "high-quality qualitative research is marked by a rich complexity of abundance". Richness is generated through a "requisite variety" (Weick, 2007, p.16) of "theoretical constructs, data sources, contexts and samples" (Tracy, 2010, p.841). In addition, rigour provides face validity (Golafshani, 2003) and is also judged by

"the care and practice of data collection and analysis procedures" (Tracy, 2010, p.841). There are various means, practices and methods through which to achieve a rigorous study. However, my study proved to be rigorous judged by the care and practice of data collection and analysis procedures.

While coding, I used the constant comparative method at every step in the process. This means that I compared data with data, data with code, and code with code, to find similarities and differences (Tracy, 2010). During this study, the phenomenon of patient education within in inpatient setting was complex and multifaceted. Many dedicated field hours generated an abundance of data. In adherence to a constructivist grounded theory study, the constant comparison method was needed in order to make sense of the data set. At the beginning of the study, I quickly realised that my field notes, observations and interviews were lacking a certain level of breadth. As the study unfolded and constant comparison methods had commenced, rigour was enhanced by the level of transcription and observation details, more comprehensive interview questions, and more engagement in reflexive memos. Field interviews and direct observations enabled me to collect unique and new data which added valuable contributions. However, constantly comparing this new data that emerged is what provided me with meaningful and significant knowledge claims.

## 1.3.9.2    Sincerity

According to Tracy (2010), "sincerity as an end goal can be achieved through self-reflexivity, vulnerability, honesty, transparency, and data auditing" (p.841). I believe that sincerity has always been present throughout the study; however, the level of engagement with self-reflexivity and transparency methods has evolved. Particularly important with observational methods, I became self-aware of my own positioning and motivations that could have influenced the way I collected and analysed data. For this reason, I always added reflexive memos at the end of each participant transcription and direct observations. When I needed to go back to those documents, code my data set or look for emerging themes, I didn't only have the transcription or field notes themselves, but reflexive memos to consult. This was integral to the process as it heightened personal

awareness as to how I came to make judgements about a particular encounter and how this played a role in the methods, successes and mistakes of the study.

## 1.3.9.3    Credibility

Credibility refers to "the trustworthiness, verisimilitude, and plausibility of the research findings" (Tracy, 2010). According to Tracy (2010), it is achieved through "practices of thick description, triangulation or crystallization, and multivocality and partiality" (p.842). In order to illustrate the data's complexity, providing enough details on the context, the iterative process of the data collection and analysis and the emergence of themes was necessary. This was attained by accounting for the complex specificity and circumstantiality of the data (Geertz, 1973).

These rich details emerging from the data also helped me ascertain a certain level of tacit knowledge within this setting. According to Altheide & Johnson (1994, p. 492) tacit knowledge is "largely unarticulated, contextual understanding that is often manifested in nods, silence, humor, and naughty nuances". Reiterated by Tracy (2010), accessing tacit knowledge takes significant time in the field. Though I do not consider myself to be an expert in understanding all aspects of this particular setting, I do believe that I was able to notice and document certain hidden assumptions and meanings that had guided "individuals' actions whether or not participants explicitly say so" (Tracy, 2010, p.842). As the study progressed, I started to notice certain patterns in behaviours of both patients and health care providers. Having the ability to sit in on conversations and observe interactions enabled me to notice cultural values within this inpatient setting. For example, starting data collection, I focused on taking notes of who was talking, what they were talking about, how it related to patient education and who this conversation was being directed to. Once I established a certain level of basic understanding, I also started to take note of who wasn't talking, what wasn't being said and how this unarticulated behaviour was being manifested. The longer I was in the field, the more I realized that there are many concepts that need to be unpacked further. However, I believe this study delved beneath the surface and at some level started "to explore issues that are assumed, implicit, and have become part of participants' common sense" (Tracy, 2010, p.842).

In addition, I made use of multiple data sources/methods, and theoretical lenses, and peer debriefing with my supervisors gave me access to multiple researcher viewpoints. This was valuable to my research as it provided us with "multiple types of data, researcher viewpoints, theoretical frames, and methods of analysis that allow different facets of problems to be explored, increased scope, deepened understanding, and encouraged consistent (re) interpretation" (Tracy, 2010, p.842). I collected multiple types of data, and because of this, I was able to explore various theoretical concepts and engage in practices such as *crystallization*. The term "*crystallization*" in qualitative research refers to the idea if two or more researchers or types of data collected converge to the same conclusion, it is deemed more credible (Denzin, 1978). Consistent with a constructivist grounded theory study, the term "crystallization" is used instead of "triangulation" as we recognize that our findings are shaped by the circumstances of their production, even if multiple data sources/methods were used and numerous researchers with varying theoretical frameworks contributed to the study (Tracy, 2010).

## 1.3.10    Ethical considerations

As this study included the participation of human subjects, the 2nd Edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans required review and approval by the Western University Research Ethics Board (REB) before the research had started. The Western University REB had approved this study (ID #6822, Appendix F). In addition to this approval, I had to complete various training modules before I was able to start preliminary observations, including the Tri-Council Policy Statement: CORE training, Lawson's Standard Operating Procedures for Clinical Research Module, Lawson's Privacy and Confidentiality training, hospital mandated and clinical research training.

There are many steps that were taken in order to ensure that as a researcher I followed the human dignity ethical principles when interacting with the human subjects. Firstly, the methods section describes the purposeful sampling strategy that was utilized throughout the study ensuring that the participants we selected to be part of the study could meaningfully contribute to theory building associated with constructivist grounded theory methods and ensured that I achieved maximum variation in my observations of patient

education within the inpatient setting. Both the key informants and caregivers participating in the study first read an informative overview of the study, detailing the nature of the study, the study procedures, the risks/harms and benefits of the study, their rights as a participant, the voluntary nature of their participation in the study, as well as the researcher's contact information (Appendix C-E). Once the information letter had been read and any questions are answered, participants were provided with a consent form to read and sign and were given a copy.

This study involved minimal risks at the individual level for participants, the most significant of which was the risk of feeling self-conscious about being interviewed and potentially disclosing sensitive health information. Participation in the study was fully voluntary and participants had the right to not answer individual questions, or to remove themselves from the study at any time. Participants' information was stored on a password-protected, secured network server and participants' names are not associated with the results obtained from this study.

## 1.4     Outline of the thesis

This thesis follows an integrated article format. Chapter 2 is a stand-alone article that was written for *Patient Education and Counselling* which focuses on two of the three research questions. As a result, the article is only 4000 words long and includes the findings in a table rather than integrating them into the text to comply with the journal's length requirement. Its main focus is on timing and interprofessional teams, and it doesn't have the chance to expand and address other themes. Therefore, Chapter 3 picks up the other themes, particularly sociotechnical: role of the boundary object. It provides a discussion of the findings overall, reflections on the process of conducting the thesis project, limitations, implications for professional practice and clinical education and personal takeaways.

# Chapter 2

## 2    Overview

This chapter an article to be submitted to *Patient Education and Counseling*. The journal's word limit is 4000 words exclusive of tables and references. The tables to be included with the article submission are included in this chapter. I have supplemented these with more data examples in Appendix G and H. I have flagged these in the appropriate sections in the paper below.

Co-authorship statement: Talia Di Marco conducted the data collection process and wrote the article drafts. These drafts were sent back and forth with Dr. McKenzie and Dr. Goldszmidt who provided multiple suggestions in editing the article and contributed in the data analysis.

## 2.1    Abstract

Objective: To provide insights on how patient education (PE) is enacted in an inpatient Internal Medicine Inpatient Unit at an academic teaching hospital in Ontario, Canada that has adopted Patient Oriented Discharge Summaries (PODS)

Method: A constructivist grounded theory methodology was conducted for 106 participant observations and 25 field interviews.

Results: We found that (1) patient education was not a single event but occurred at multiple *moments* throughout the course of care, and many components were required for PE to be effective (2) In addition to needing everyone in the same room, there needed to be an alignment of goals and concerns between the health care providers (HCPs), patients (Pts) and family advocates (FAs) (3) Team logistics and schedules meant that the same category of HCPs were present but not the individuals themselves.

Conclusion: This study identifies a host of features that need to be attended to for effective re-engineering of inpatient PE throughout a hospital stay.

Practice implications: Designing a better system for PE in the IMIU requires addressing all the levels of complexity as the current re-engineered discharge tools do not adequately address the barriers to having a PE conversation at the point of discharge.

## 2.2    Introduction

Patient education (PE)[2] is widely recognized as an important component of effective care in all health care settings. However, PE research and best-practice guidelines across many health professions (e.g., Johns, 2012; Syx, 2008; Zangi et al., 2015) rest on a number of implicit and explicit assumptions (Silverman, Kurtz, & Draper, 2016) that may limit their applicability to important inpatient settings. First, they focus largely on specific patient conditions or single acute illnesses or procedures (e.g., Giraudet-Le Quintrec et al., 2003, Oliver et al., 2001, Mcgowan, 2011). Second, they emphasize interactions between single health care providers (HCPs) and single patients (e.g., Giraudet-Le Quintrec et al., 2003; Zangi et al., 2015). Third, an information transfer model is assumed, with patients as the recipients and HCPs as the providers (Lee & Garvin, 2003). Lastly, there is an assumption that PE takes place as a formally scheduled intervention; in inpatient settings at the point of discharge (Knier et al., 2015).

These assumptions do not reflect the complex context of the internal medicine inpatient unit (IMIU), where the majority of patients suffer from at least three chronic medical conditions (Zulman, et al., 2014). Changing patient conditions and the emergence of new information may require multiple PE moments. In addition, the IMIU is an interprofessional team environment, with a shifting roster of health care providers (HCPs) engaging with patients throughout the stay. Finally, the complexity and advanced age of most IMIU patients may draw family advocates into their hospital care and their PE. Without research and guidance that reflect these conditions, inpatient services that provide care to such patient populations are left to develop strategies without an evidence base.

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[2] See Appendix A for list of acronyms

The small body of research on PE in IMIUs has focused on the point of hospital discharge (Pinelli, et al., 2017). Discharge has likewise become the target of hospital-wide quality improvement initiatives with the goal of reducing readmissions. Evidence-based discharge education models such as the Re-Engineered Discharge Process (RED) have been a part of this move (Jack et al., 2013). While improving the discharge process is clearly important, it may not fully capture the PE needs in an IMIU setting.

This article provides findings on how PE is enacted in an inpatient IMIU at an academic teaching hospital in Ontario, Canada that has adopted Patient Oriented Discharge Summaries (PODS), a quality improvement process for standardizing PE at discharge that incorporates several re-engineered discharge process components (Hahn-Goldberg et al., 2016). The authors demonstrate that this setting is characterized by PE moments that take place during regular and daily clinical encounters between patients, family advocates, and HCPs throughout the course of the hospital stay.

## 2.3    Methodology

The study methodology was constructivist grounded theory (CGT) (Charmaz, 2014), which focuses on the exploration and understanding of social phenomena and has been used successfully in other research to develop and expand theoretical models of professional practice (Komaromy et al., 2018; Levack et al., 2011). The study was approved by Western's Health Sciences Research Ethics Board (HSREB).

### 2.3.1 Research setting

The studied IMIU has three interdisciplinary teams, each led by an attending physician and including many HCPs. Physician team members include senior medical residents (in their 2nd and 3rd years of post-graduate training (PGY), junior residents in their first PGY), and senior medical students (in their 3rd and 4th year of a four-year training program). Health care team members included a social worker, a physiotherapist, an occupational therapist, a patient care facilitator (a nurse whose role is to coordinate discharge planning and communication between team members), a pharmacist, a speech language pathologist, a dietician, a home care coordinator and bedside nurses. The nurse-patient ratio is 1:4, with the same ratio typically being used for medical students assigned

to patients. Depending on the team's daily census, the resident-to-patient ratio ranges from 1:5-1:8. There are three IMIU teams on the ward; nurses are split between teams, e.g., with 2 patients from 1 team and 1 patient from each of the others. HCP schedules vary (Bilodeau et al., 2020). Some work regular Monday to Friday hours and some work shifts that rotate on a short-term or longer-term basis. This variation results in constantly shifting team composition (see Table 1). The presence of family advocates/caregivers also varied, with more present on weekends than during weekday business hours.

**Table 1. Team schedules and availability**

| Participant type | Weekday availability | Weekend availability | Schedule rotation |
|---|---|---|---|
| Nurse (N) | 7am-7pm/7pm-7am | 7am-7pm/7pm-7am | 3 days, 2 nights[3] |
| Physiotherapist (PT)[4] (1 per team) | 8am-4pm | 8am-4pm (1 for 3 teams) | 5 days on, 2 days off |
| Occupational therapist (OT) (1 per team) | 8am-4pm | 8am-4pm (1 for 3 teams) | 5 days on, 2 days off |
| Patient care facilitator (PCF) (1 per team) | 8am-4pm | none | 5 days on, 2 days off |
| Pharmacist (PH) (1 per team) | 8am-4pm | none | 5 days on, 2 days off |
| Home care (HC)* (1 per team) | 8am-4pm | 8am-4pm (1 for 3 teams) | 5 days on, 2 days off |
| Social work (SW)* (1 per team) | 8am-4pm | 8am-4pm (1 for 3 teams) | 5 days on, 2 days off |
| Registered dietician (RD) (1 per team) | 8am-4pm | none | 5 days on, 2 days off |
| Medical student (MS) (3-4 per team) | All present 8am-6pm (1 overnight on call per team when R1 not on call) | One per team present 8am-6pm and on call overnight if a R1 not on call | 6-week rotations |
| Resident (R) (3-4 R1 per team – 2 Senior R per team) | All present 8am-6pm (1 R1 overnight on call | One R1 per team present 8am-6pm and on call | 4-week rotations |

[3] *Nurses on the IMIU had several varying schedules, however this schedule rotation was the most commonly observed*

[4] *(PT/OT/HC/SW): For the most part, schedule rotations were 5 days on/2 days off, Monday through Friday. Occasionally, some HCPs were covering weekends.*

| | per team when medical student not on call. One senior R1 across the three teams per night) | overnight. One senior R per team until all patients have been rounded on. | |
|---|---|---|---|
| Attending (Att) (1 per team) | 8am-6pm | 8am until rounds completed for the day | 2-week rotations |

A typical day on the IMIU during the observation period saw 25-35 patients assigned to each team, and the number of admissions and discharges per day ranged from 2-8/team. The hospital prioritized discharging patients prior to 11 AM or, at the latest, 2 PM. In reality, we observed that discharge could take place at any time, and neither nurses nor other team members had explicit time built into their schedules for conducting discharge education.

Standardized PE at discharge was supported by PODS, an instrument developed collaboratively by health care providers and patients. Its implementation is supported by ARTIC (Adopting Research to Improve Care), a joint program of the Council of Academic Hospitals of Ontario and Health Quality Ontario. According to Health Quality Ontario, PODS *"provides patients with easy-to-understand instructions upon discharge that also facilitate a tailored and clear discussion between health care providers and patients on what the patient needs to know and do once they return home."* The instrument can be accessed through the patient's electronic health record and is accessible to all team members. Whereas RED assumes that a team will include a designated discharge educator, PODS does not. PODS is designed to be reviewed by the physician with the patient prior to discharge to summarize what happened during the hospital stay, explain what changes patients should expect after discharge, describe follow-up plans, flag medication changes, and identify who to contact if problems develop (Hahn-Goldberg et al., 2016).

## 2.3.2 Data collection

After securing informed consent, one of the authors (TD) collected data through non-participant observations and 25 recorded 10-45-minute field interviews with patients, family advocates, health care providers, and physician team members. TD observed each of the three teams and observed 106 participants. Patient participants ranged in age from 19-99 years and were sampled broadly for age, gender, availability of family advocates and variety and complexity of clinical condition(s) (refer to Table 2 for participant breakdown)

**Table 2. Participant breakdown**

| Participant type | Extended period of shadowing[5] | Brief observation periods[6] | Total |
|---|---|---|---|
| Patient (Pt) | 9 | 34 | 43 |
| Family advocate (FA) | 1 | 17 | 18 |
| Nurse (N) | 2 | 8 | 10 |
| Physiotherapist (PT) | 1 | 2 | 3 |
| Occupational therapist (OT) | 1 | 2 | 3 |
| Patient care facilitator (PCF) | 3 | 0 | 3 |
| Pharmacist (PH) | 0 | 2 | 2 |
| Home care (HC) | 1 | 2 | 3 |
| Social work (SW) | 1 | 1 | 2 |
| Registered dietician (RD) | 1 | 0 | 1 |
| Medical student (MS) | 1 | 4 | 5 |
| Resident (R) | 5 | 2 | 7 |
| Attending (Att) | 0 | 5 | 5 |
| | | | |
| **Total** | 26 | 79 | 105 |

*Total field interviews*: 25 [ 9 patients, 2 family advocates, 2 nurses, 3 patient care facilitators, 1 home care worker, 1 social worker, 1 registered dietician, 2 medical students, 4 residents]

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[5] Pre-scheduled opportunities where TD shadowed an individual over several hours and often on more than one occasion.

[6] Observations that took place in the context of team rounds, and subsequent opportunities that arose as team members went to visit individual patients, or when observing small group interactions

Data collection took place during 26 study days (127 field hours) from September-November 2019. Most study days started at 8:00 am and ended around 2:00pm, with some evening, early morning and weekend observations. TD observed interactions and written education and communication practices among HCPs and patients. Initial sampling was purposive to maximize variation in times of day, days of the week, type of HCP, ongoing team interactions versus new team member changeovers, and different schedules in relation to shifting team memberships. As the study proceeded, the team moved toward more theoretical sampling to test the developing theory and seek both confirmatory and negative cases. Data collection continued until theoretical sufficiency was reached, which did not mean that "no new ideas would have been identified with more data collection, rather we had achieved sufficient data collection to enable an understanding of the dimensions of interdependence" (Dey, 1999). Collected data included interview transcripts, field notes describing oral and written education practices observed on the IMIU, as well as clinical documentation used for education purposes.

## 2.3.3 Data analysis

TD transcribed the interviews verbatim after each study day. Anonymized field notes and transcripts were stored on a password-protected computer and uploaded to Nvivo 12. Consistent with a CGT methodology, data analysis moved from initial open codes to a set of focused codes and finally towards theoretical coding (Charmaz, 2014). Data collection and analysis was an iterative process; as new insights emerged, data collection and sampling strategies were modified. A constant comparison approach ensured the application of new insights and new codes to previously analyzed data. Rigour was ensured through a combination of constant comparison, reflexive memoing to acknowledge researcher position and perspective, methodological triangulation through multiple data collection methods, and theoretical triangulation. Our research team comprises TD, a master's student in Health Information Science (TD), an MD/PhD internist with expertise in medical education and communication theory (MG), and a PhD in Library and Information Science (PM). Members of the research team met bi-weekly to discuss initial open coding and emerging and common themes. The analysis led the team to identify gaps that drove theoretical sampling for subsequent recruitment. This

process enabled the emergence of major analytical categories and subcategories that led to the abstract theoretical understanding of PE in the studied context.

## 2.4    Results

PODS was designed to consolidate and standardize PE at the point of discharge, but our most significant finding was that inpatient education did not occur at a single scheduled or set moment in time. Rather, we identified a continuum of possible and actual educational *moments* throughout a patient's hospital stay.

Some moments were taken up as opportunities for PE, and other opportunities were missed. The size and complexity of the care team meant that different health professions were expert on different aspects of the patient's condition and care. However, the complexity of HCP schedules made it difficult to reach the right kind of HCP at the right time. The rotation of individual HCPs on and off duty meant that, even when the right kind of HCP was available, the individual on duty may not be the one who made the treatment decision or recommendation under discussion and may not know the full details. Conversely, when the right HCP was available, absent family caregivers or patient confusion or cognitive impairment were barriers to mobilizing PE moments effectively.

My understanding of effectiveness emerged from our discussions with HCPs, patients, and family advocates about what they were trying to achieve: a process that ensures from the patient's perspective that their needs were met. This included presenting the right topic at the right time, with the right people present, with some degree of patient engagement to indicate receptiveness and understanding. PE moments that HCPs, patients, and/or family members understood as effective shared several characteristics, which we describe here. The first part of Table 3 and Appendix G provides illustrative data.

**Table 3. Effective and unsuccessful education moments**

| 1. Effective education moments | a. Open lines of communication across the team | *Field note: During the morning rounds, the **MS3[7]** mentioned to **R3** and **PCF M** that a particular patient had many questions to do with goals of care and the meaning of "full code" status. They confirmed with the nurse his current status. The HCPs sat down with the patient and went through each status level to make sure the patient could "fully understand what's happening to them" R3.* |
|---|---|---|
| | b. Presence of all relevant team members | *Field note: Scheduled family meeting with **6 HCPs** present and Pt 23 with family. **R3** stated that this purpose was to negotiate a "well-coordinated home plan to not get you back here".* |
| | c. Presence and engagement of patient and/or advocate | *Field note: **R2** went to discuss the results of **Pt 14** leg CT. Pt 14 was laying on one side of the bed, in a lot of pain, dozing in and out when questions were directed to her. **3 FA's** were present during the encounter: 1 FA was asking questions about the results, another was keeping Pt 14 calm, and the other was taking notes.* |

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[7] Legend of pseudonyms: Att=Attending, FA= Family advocate, HC=Home care coordinator, HCP= Health care provider, MS= Medical student, N= Nurse, OT= Occupational therapist, Pt= Patient, PCF= Patient care facilitator, PH= Pharmacist, PT= Physiotherapist, RD= Registered dietician, R= Resident, SW= Social worker

| 2. Unsuccessful education moments/ missed opportunities | a. Misaligned timing of PE moments over the course of the inpatient stay | *Field note: Nurse was presenting and overview of the PODS to Pt 12. As she was reading aloud, Pt 12 was getting up and packing. Not much seemed to be registering with the patient […] "Are we done yet? I want to go home" Pt 12.* |
|---|---|---|
| | b. Minimal communication across the inter professional team | *"As a nurse, we are the most accessible staff member for the patients. So, we tend to be the person who has to answer their questions" N1. Many times, the PH will have implemented a med change, but they don't indicate why […] "So when patients ask, we don't have a good answer for them" N1.* |
| | c. Failure to verify patient/advocate engagement and understanding | *Field note: Pt 31 was very confused and was partially deaf. R4 discussed with her that they found two tumors but needed to test if they were cancerous. "If they aren't benign, chemotherapy/radiation would be administered" R4. Pt 31 nodded […] When the R4 spoke to the FA over the phone, she found out Pt 31 had told the FA that treatments would start right away.* |
| | d. Misalignment of goals and concerns between HCPs and patients/advocates. | See Table 4 |

## 2.4.1 Open lines of communication

For example, gathering for morning rounds enabled team members to communicate as a group. This provided an opportunity for HCPs to raise concerns and clarify points with colleagues that led to the sharing of beneficial information and enabled team members to be in alignment when addressing this information with the patient (Table 3, 1a; Appendix G Table 3, 1a)

## 2.4.2 Presence of all relevant team members

Scheduled family meetings often proved to be effective as team members and advocates were gathered in the same room, affording honest and open negotiations (Table 3, 1b; Appendix G Table 3, 1b). Bringing all the right people together at the right time contributed to effective PE.

## 2.4.3 Presence and engagement of patient and/or advocate

When patients were not able to meaningfully engage due to health or cognition problems or to lack of interest, the presence of an engaged advocate became essential (Table 3, 1c; Appendix G Table 3, 1c). In the hectic IMIU environment, with many HCPs assessing and managing patients, a family advocate can support effective PE moments. They may have information about the patient's condition, history, or communication style that allow them to support patient care and education. We found that they may function as intermediaries (Wathen et al., 2008), both seeking and providing information.

The second part of Table 3 shows how the absence of any of these criteria may result in educational opportunities being missed.

## 2.4.4 Misaligned timing of PE moments over the course of the inpatient stay

We observed numerous instances where misaligned timing compromised effective inpatient PE. In some cases, HCPs visited at times that didn't work for the patient and no advocate was present. In others, misalignment arose from when during the stay PE

occurred. Providing PE either too long before discharge or at the point of discharge often resulted in missed opportunities.

In many instances, allied HCPs provided education or information when they completed their care and signed off on the patient prior to discharge. The gap in time between any one HCP's sign-off and the time of discharge means that education materials might be given to the patient by different HCPs over the course of the stay.

Although providing PE at the point of discharge meets HCPs' goals by providing an opportunity to consolidate educational messages from across the hospital stay, it was often unsuccessful. There was a lack of consensus among the physician team and nurses about who should be having the PODS discussion with the patient. As R4 stated, "we don't really have any training on PODS, so we aren't really sure how it's supposed to be delivered". The irregularity and unpredictability of the timing of discharge meant that the ideal person was often not present to go over the PODS with the patient. Finally, we found that in the minutes leading up to discharge, the attention of many patients and family advocates was fully focused on getting out of hospital and they were not receptive to patient education (Table 3, 2a). The designated educational moments did not align with moments when the patient was prepared or ready to receive that education.

## 2.4.5 Minimal communication across the interprofessional team

The complexity of team composition and timelines meant that individual HCPs might be out of the loop on the patient's current status. This was particularly evident when the original HCP was not available to answer questions that pertained to their specific role within the interdisciplinary team (Table 3, 2b).

## 2.4.6 Failure to verify patient/advocate engagement and understanding

Patients and advocates often "nodded along" to explanations, so if HCPs failed to probe or verify understanding they might wrongly assume that patients/advocates were aware of what was happening to them and why (Table 3, 2c). This lack of clarification resulted in many missed educational opportunities.

## 2.4.7 Misalignment of goals and concerns between HCPs and patients/advocates

Underlying PE moments was the fact that the complexity of the patients, the involvement of family advocates, and the diversity of the interprofessional team resulted in different participants having different concerns. These differences, such as the mismatch at discharge between patients' concern about going home and HCPs' concern with PODS, compromised the effectiveness of PE. All participants discussed or demonstrated concern with daily living in hospital, an ever-changing clinical team, coping with illness and long-term transitions, and "going home with certainty" -- being able to leave hospital without fear of readmission (see Table 4). However, patients and family advocates understood and perceived many of these concerns differently from the HCPs, and members of the care team understood them differently from one another. Effective PE occurred when patient concerns intersected with what HCPs thought was important.

**Table 4. Patient vs HCP concerns**

| Concerns | Patient and family concerns | HCP concerns |
|---|---|---|
| 1. Concerns of daily living in hospital | a. Hospital food<br>*"I need food to survive, real food […] I want a nice slice of pizza from the cafeteria"* **Pt 35.**<br>*Field note: The* **CG 1** *was getting very frustrated that there was more waiting required as she said her mother actually "wants to eat now".*<br>b. Hospital atmosphere<br>*"[…] The only thing I need to do the next time is to have my own room […] that's a very VERY big thing for me"* **Pt 3.**<br>c. Dealing with underlying anxieties<br>*"There's so many more things that affect my dialysis and no one really takes that into account. […] I've had several anxiety attacks while I was on dialysis. […] So every time that blood pressure alarm goes off, it triggers me and it's just a cycle"* **Pt 20.** | Timing<br>d. *Field note:* **R5** *explained that she had a half day today, which meant that all her patients had to be visited this morning. When visiting,* **Pt 36**, *she did not speak English and, there was no family present at that time for translation purposes. R5 flagged that Pt 36 would have to be visited at another time by the team when the family was present as she had to leave.*<br><br>e. *Field note:* **SW M** *had to tackle many social issues with Pt 24.* **N2** *and* **PT L** *were waiting to assess patient. No family present, SW M looked at the door back and forth 8 times and rushed the interaction.* |

| | | |
|---|---|---|
| 2. Concerns of an everchanging clinical team | a. Lack of clarity in team's roles<br>*"This is a cycle, and everyone needs to start talking" […]* **Pt 19.**<br>*Field note:* **Pt 19** *and her POA were unimpressed that someone told them "it's not my job". To them, this is more than just a job.*<br>b. Patient-HCP trust<br>*"No one is listening to me, they don't believe me"* **Pt 12.** | c. Availability of the team member with expertise at the right time<br>*See Table 3, 2a, i.* |
| 3. Concerns with coping with illness long term and transitions | a. Getting back to baseline<br>*"I want my blood sugar back where it should be. I realized it can't be instant […] but they got to do something they can't just kick me out"* **Pt 6**.<br>b. Discharge disposition<br>*Field note: Pt 13 has bipolar disorder and type 2 diabetes. Though unstable, very adamant on going home. Without any family or friends to take care of him, the suggested long-term care facility was quickly denied. "I'm not getting discharged today… and I'm tired of hearing that"* **Pt 13**. | c. Dealing with the active issues<br>*"I addresses the active issues first and I really just need to know if the patient is still symptomatic"* **R5.**<br>d. Dealing with the complexities of pts<br>*Field note:* **R2** *and I exited the room and told me that many times with such acute multisystem issues, he doesn't know what he's going to say or how he is going to say it to discuss with the patients as he wants to give them information but not overwhelm them.*<br>e. *Exploring discharge disposition*<br>*Field note: During Pt 23 family meeting, Pt 23 reiterated many times he wanted to go home. While the FAs weren't certain they could provide enough support. The R3 and the HC worker went back and forth with Pt 23 and FAs as it was a battle to choose between going to a nursing home or coming up with the funds to provide more constant care at home.* |

| | | |
|---|---|---|
| 4. Going home with certainty | a. Not wanting to be readmitted<br>*"My main concern…just getting out too soon and having a relapse and ending back in like a day or two"* **Pt 5.**<br>b. Managing life at home<br>*"I need numbers, contacts […] to check into my system at home like with my cleaning. I can't do my housework on my own anymore* **Pt 5**.<br>c. Simply wanting to go home<br>*"I just want to go back home. I want my bed; I want things back to normal"* **Pt 23**. | Reducing readmissions<br>d. *Field note:* **PT L** *repeatedly talks about issues/education throughout patients' stay "it's got to stick in patient's heads, they need to be able to navigate at home".*<br>e. *"At the end of the day, we want to reduce readmission. People want information but what they do with it is up to them"* **N1.**<br>f. *"If they understand it, they'll be more inclined to do it, and it reduces the chance of them coming back for the same issue"* **Att 1.** |
| 5. Other PE challenges identified only by HCPs | | a. Limited workspace<br>*Field note: Many times, the* **HC L**, **PH L** *and medical students expressed the inconvenience of not having enough workspace for their in-depth patient assessments.*<br>b. Efficiency<br>*"Patients have many stories to tell that are irrelevant, you don't want to waste time"* **MS 3**.<br>c. Proper referrals<br>*"The biggest mistake the physician team makes is the fact that they don't always put in the right referrals for us"* **RD M**.<br>d. Variability of attending styles |

| | | *"Sometimes you don't do things in a typical way because of the variety of attendings that constantly shift"* **PCF M**. |
|---|---|---|

### 2.4.7.1    Concerns of daily living in hospital

Concerns of daily living in hospital that were top-of-mind for many patients and family members and focused on the daily struggles of being a patient in an IMIU (Table 4, 1 a-c; Appendix H Table 4, 1 a-b). HCPs were more concerned about prioritizing the timing of their daily tasks and encounters around other happenings in the hospital day (Table 4, 1 d-e).

### 2.4.7.2    Concerns of an everchanging clinical team

Many patients and families expressed concerns about the nature of their relationship with the interdisciplinary team (Table 4, 2 a-b), whereas allied HCPs were more concerned about the availability of specific team members and their expertise when they were required (refer back to Table 3, 2a, *i*).

### 2.4.7.3    Concerns with coping with illness long term and transitions

Patients and families expressed concerns with coping with illness long term and transition and sought answers based on their previous experience of their chronic condition(s) (Table 4, 3 a-b). The care team seemed to prioritize dealing with patients' active issues. HCPs focused more on dealing with patient's multisystem issues and exploring the supports that could be offered at the patient's discharge disposition (Table 4, 3 c-e).

### 2.4.7.4    Going home with certainty

Going home with certainty seemed to be the only concern that all participants could agree on. Though expressed in different ways, our observations indicated that patients, family members, and the medical team all shared the goal of getting the patient out of hospital without the need for readmission (Table 4, 4 a-f).

HCPs identified further challenges: access to limited workspace, prioritizing efficiency, getting the proper referrals and the variability of attending styles (see Table 4, 5 a-d; Appendix H Table 4, 5 c-d).

## 2.5    Discussion and conclusion

### 2.5.1 Discussion

We set out to study PE at discharge to understand how PODS operated in the IMIU setting. What we found instead was a far more complex system, which includes a host of features that need to be attended to for effective re-engineering of inpatient PE. Whereas Re-engineered Discharge (RED) initiatives have identified fundamental PE components for the point of discharge, the complexities of the IMIU make these challenging to implement. In addition, the focus on discharge does not address the multiple moments of PE throughout the IMIU stay, the constantly shifting membership of the interprofessional team, patient complexity, the presence of family advocates, and the arc of patient and family learning needs over time. A full PE model for this setting therefore requires a fundamental rethinking to respond effectively to this complexity.

First, HCPs are trained to educate and communicate within the context of a one-off encounter with a patient (Silverman, Kurtz, S., & Draper, 2016). In contrast to more commonly studied PE contexts such as surgery, oncology, or diabetes (e.g., Giraudet-Le Quintrec et al., 2003, Oliver et al., 2001, Mcgowan, 2011), multiple layers of complexity mean that team members advise patients and families at different times through the course of the inpatient stay and with different perspectives, approaches and schedules. At the patient level, the presence or absence of family members can have a significant impact for patients unable to advocate for themselves (Lamore,K., 2017). At the HCP level, constantly varying schedules pose a challenge. The availability of each HCP specialty, and of each individual HCP, differs on a daily basis, which makes it very difficult to get all the right people in the right room at the same time. These multiple layers of complexity in the IMIU make it extremely challenging to achieve the ideals of coordination, communication, and shared ideas among interprofessional teams (Falvo, 2010). To ensure effective PE in an IMIU, hospitals will need to develop models that can effectively support multiple communications.

Second, education needs vary across time. Early in the stay, patients need to be oriented to how the system works and what happens. Team members need to introduce

themselves, so patients become familiar with their role and understand how best to engage with the different members of the complex care team. Patients who require family advocacy or support need to be provided with a coordinated way to interact with the care team throughout the hospital stay (Burm et al., 2019). As the stay progresses, numerous other topics need to be addressed including conventional PE topics such as "what is my health problem?", "what do I need to do?" and "why do I need to do this?" (Byrd, J., & Thompson, L., 2008) and topics related to going home safely – which, for some patients and families, appears to be their top concern.

As much as scheduled formal discharge communications are needed, more attention should be paid to the patient care-related interactions that appear to arise serendipitously, as these have been shown to support the spontaneous and opportunistic needs of patients and HCPs (Burm et al., 2019; Lewin & Reeves, 2011). While we observed informal education encounters that responded effectively to changes in patient information over the course of the stay, more commonly we observed lost opportunities for supporting patients and their families because they were not scheduled events and team members had little flexibility in their day to adapt to impromptu requests for meeting. Moreover, the emphasis on discharge as the primary "educational moment" failed to acknowledge patients' competing priorities at this time; for many, their focus on the logistics of getting out of hospital meant that they were distracted from, or did not want, the PE being offered at that time. Therefore, if hospitals take up the idea of education across time, they need to consider how to build this into HCPs' busy schedules and how to adequately inform patients and family members how and when to take advantage of these opportunities.

Third, PE guidelines assume a more-or-less linear process in which HCPs assess patient needs and then plan, implement, and evaluate an educational strategy (Falvo, 2010). This can be an effective strategy for a single-system admission. However, complex diagnoses, multiple morbidities, and ongoing changes to the patient's condition in the IMIU make a linear process impossible. We observed that education and decision making often overlapped in interactions between the care team and the patients/families, resulting in negotiation between the patients/families and the HCPs as well as among the IMIU team

members. Not uncommonly, the team continued to get new information throughout the patient's stay, including from the team and family members who might gather together for a PE session. Therefore, decisions regarding treatments, safety at home, transitions, social services and available resources were often being made in conjunction with education. The team needed to adapt quickly to new knowledge in order to support PE. Linear PE models therefore require major modification if they are to provide good guidance for the overlapping complexities of a fast-paced, interdisciplinary IMIU.

Finally, it is also important to acknowledge that for some patients there may be no "right" moment to educate; depending, for example, on the patient's lucidity, the presence or absence of family advocates, the availability of HCPs, or the complexity of the illness(es). For these reasons, post-discharge follow-up may be needed to supplement inpatient and discharge education. For some patients we observed, PE was only effective over multiple admissions; for these patients, the most effective form of patient education was the experience of failing to attend to post-discharge recommendations and being readmitted.

## 2.5.2 Limitations

We recognize that our understanding of patient education in an IMIU is incomplete. Having one researcher collect the data provides merely a glimpse of the PE moments that occurred in this setting. Additionally, while we did attempt to observe the presentation of PODS and other educational materials, we were not able to identify the ways in which they were or were not taken up after discharge. Ultimately, the unravelling of the patient education moments of interprofessional collaboration is an interpretation. Due to the contextual nature of the study, our findings are not directly transferable to other inpatient settings. Rather, it offers a depth of insight that can be taken up by others to explore their own contexts.

## 2.5.3 Conclusion

Designing a better system for PE in the IMIU requires addressing all the levels of complexity. Discharge re-engineering tools like the re-engineered discharge process (RED) and PODS support effective discharge education but do not adequately address the

barriers to having a PE conversation at the point of discharge. Nor do they address the many moments of PE that occur before discharge. Re-engineering effective inpatient PE for the IMIU setting requires attention to the many moving parts: complex diagnoses and medical conditions that change over the course of a stay, an interprofessional team with varying schedules, and the possibility of family members playing a significant role in both patient uptake of PE and in HCP understanding of the patient's condition and context. While this study does not offer a single solution, these rich insights can be used to help hospitals consider how they can acknowledge these complexities to achieve better outcomes in relation to PE.

# Chapter 3

# 3    Introduction

Chapter 1 introduced the problem and gap, reviewed the literature, and presented the study purpose and design. Early in my data analysis, I discovered that patient education took place at any time throughout the hospital stay on multiple occasions. This significant finding became the primary focus of the stand-alone article draft presented as Chapter 2, which was written for *Patient Education and Counselling*. Writing a journal article provided me with an opportunity to really focus on my findings and present them concisely. However, the journal's 4000-word limit gave limited space to share and elaborate on findings. For this reason, Chapter 3 will provide more detail on how this study answers the research questions and contributes to the gaps in the literature.

In Chapter 1, I identified five major gaps in the literature. These gaps centered around 1) the lack of research and guidance on patient education in more complex settings for patients with multi-morbidity, 2) the little attention given to patient education in an interprofessional context, 3) the overwhelmingly health care provider centric literature on patient education, 4) the assumption that patient education is conveyed at a single moment in time, 5) and the lack of attention to sociotechnical relationships among people and tools.  To address these gaps in the literature I sought to answer the following overarching research question with three sub-questions:

*How is patient education enacted in an inpatient internal medicine setting in a teaching hospital?*

- o *How do various health care professionals interact with one another, with the patient, and with family advocates?*
- o *Are there documents or objects that function as boundary objects in support of patient education?*
- o *When does patient education happen?*

The article addressed the first and third sub question. This chapter addresses the sociotechnical gap in the literature and the role of boundary objects that I was not able to address in the article. It then provides a discussion of the study's contributions to the research literature overall, reflections on the process of doing the thesis, limitations, and implications for professional practice and clinical education.

## 3.1 Fleshing out the findings

This study has centered around the complexity of the IMIU setting. We know that health information seeking, and mediating processes are complex in nature as they require intensive time and resources allocated to their development (Wathen et al., 2008; Harris et al., 2010). Throughout this research, I have demonstrated that complexity is present in many aspects within the IMIU. My findings indicate that the underlying complexity of individual patients with multiple comorbidities was heightened by the presence or absence of family advocates and by the composition of health care provider team(s).

This chapter returns to sub question 2 which is hinted at but could not be adequately addressed in the paper and is fundamental to the work from a health information science perspective. In the section below, I will discuss findings in relation to this, and their implications from a health information science research perspective.

## 3.2 Are there documents or objects that function as boundary objects in support of patient education?

Chapter 1 identified a gap in the patient education literature pertaining to sociotechnical interrelationships among people and tools (Jensen & Kushniruk (2016); Keshet et al., 2013). PODS was designed to be used by a variety of people across teams to consolidate and coordinate patient education. I therefore began to this study expecting to study how PODS functioned as a boundary object. However, my findings demonstrate that at best, it was a poorly functioning boundary object. Moreover, it functioned more as a means of *infomediation* rather than *info(r)mediation*. In this section, I will address the PODS as a boundary object and discuss why it functioned poorly in relation to patient complexity, miscommunications and lack of clarity around whose role it was to deliver it. I will also address the other identified boundary objects at play, in particular people who played the

role of boundary. I will then come back to the notions of *infomediation* and *info(r)mediation* and how it played out in this IMIU setting.

Though the PODS served as a means of enabling communication and collaboration across sites (Star & Griesemer, 1989, p. 393) I did not observe the PODS to effectively function as a boundary object, for several reasons. The first was that the patients were very complex. The patients I observed were typically older and the majority suffered from at least three chronic medical conditions (Vogeli et al., 2007). The PODS served as a great way to summarize the big picture items that happened in hospital. However, according to **R4:**

   *"I noticed that it gets harder and harder to write up the PODS when the patient gets more complex"*.

As the junior trainees, medical students, and first-year residents are those in charge of the PODS writeup, I observed that many struggled to incorporate the various educational aspects that they deemed appropriate in the PODS. Patient complexity also affected the discussion of the PODS with the patient. Many of the aspects that went into the PODS weren't necessarily straightforward or simple, which meant that patients with more than one comorbidity often had a great deal of material to go over and required a lot more of the health care provider's time to explicitly go over the PODS. In addition, presenting PODS to a patient who has some form of cognitive impairment also adds to the complexity. This added challenge could take time that HCPs did not have to ensure that patients were both able and receptive to receiving the PODS, which did not always happen. In these cases, the patient advocate could be a crucial resource:

   The **PCF M** described that: "*PODS is good for patients but if they are confused or delirious, it's no good to them. Honestly, it's really for the people taking care of them*".

   **Pt 6** reiterated that: *"Well you see what she left back here (pointing to the PODS package) I'm just going to give this to my daughter [...] I won't understand"*.

Added to this, patients' complex conditions required a variety of health care providers to attend to them which caused certain miscommunications in the PODS. After shadowing each type of health care provider, I noticed that it wasn't all health care providers who added information in the PODS. The people who have access and incorporate educational elements in the PODS are the physician team, the physiotherapist, the occupational therapist and the pharmacist. This means that the other health care providers deliver and triage their own educational materials in a separate final encounter. The purpose of a boundary object is to enable different groups to work together within "a situation of multi-site work relations and requirements" (Star & Griesemer, 1989, p. 393). Moreover, while multiple members of the team could add to the PODS, for the most part only junior residents and medical students filled it out. This meant that other health care providers were providing different information at different times. Therefore, while it did fulfill a boundary between physician team, nurses and patients, it wasn't taking into account the full set of teachings that were intended to go home with the patient.

The **OT L** describes: *"PODS does not fully represent what the patient learns [...] we have our own way of teaching through our programs, I guess PODS is more just the key takeaways the patients need to know"*.

PODS did not serve as intended to integrate the multiple perspectives and expertise found on the team since there was no agreement around whose role it was to deliver the PODS and how it should be delivered. In theory, PODS is designed to be written up, printed and delivered by the physician looking after the patient. Each section is to be gone through with the patient and any questions pertaining to the PODS should be answered by the physician. When starting my data collection process, I noticed that the physician team wrote the PODS, however they would insert the PODS into the patient's file and the nurse would go over the file with the patient before they were discharged. For every circumstance in which I was shadowing the physician team, I asked the question whether they were the ones who delivered the PODS. The answers I received were quite conflicting. It is important to highlight that these quotes all come from residents, who are senior trainees and are often the front line when the attending is absent. Because they are trainees, they may take these assumptions about PODS into their own clinical practice.

**R4** stated*: "We really don't have any training on PODS […] So if we don't know how it's supposed to properly be delivered, how can we put things in properly for the patients?" […] "the nurses go through PODS in the discharge package, presenting more or less the big picture items" […] "I think of it as what I would want to know if my mom was in hospital?".*

**R5** describes that: *"I believe PODS is designed for me to go over with the patients, but I put it into the chart and let the nurse go over it […]. I don't know why it's that way, but that's how everyone seems to do it".*

**R6** mentioned: *"We were never taught how to do this… so I kind of just go with my gut feeling. I write the PODS and make sure I verbally talk to the patient before they leave, then the PODS document is given by the nurse afterwards in their discharge package".*

**Field note:** *When asked who takes care of delivering PODS, both patient care facilitators answered that they always see the nurses going through them with the patients.*

**N2** described that: "Any file that is in the chart, I go over with the patient. I typically am the one who goes over the PODS".

Regardless of who delivers the PODS, if the boundary object is functioning well, the person delivering it should be able to read, interpret and explain in more detail the information to the patient. If it is functioning poorly, the person delivering the PODS will not be able to interpret the information to elaborate or clarify any questions being asked by patient. The more effective the boundary object, the more it is truly able to *info(r)mediate,* which leads to effective uptake. On the contrary, poor functioning boundary objects don't capture adequately what they're bounding.

Numerous people potentially also played the role of boundary objects. While not commonly written about, people have been recognized as playing the role of boundary objects (Davies & McKenzie, 2004). The most effective of these was the patient care facilitator role, which was designed to bridge multiple interprofessional interactions.

However, the patient care facilitator was only available Monday through Friday from 8h00am-4h00pm and was not part of the discharge education process. The focus of their role is patient discharge planning and decision making and not to the broader set of education that patients need to help them navigate the health care system and their health.

Similar to prior research (e.g., Davies & McKenzie, 2004) I also observed that patient charts functioned as boundary objects. As noted in prior research, they did so imperfectly and can contribute to medical error. In my study I observed multiple conversations between team members where knowledge exchanges were not documented. Similarly, while interprofessional rounds at times led to rich conversations about patients, the medical students and residents who looked after those patients were often not present for those rounds and therefore neither documented the conversations nor conveyed them to the patient's or families.

Medical students and residents also served as boundary objects as they often mediate information between the attending physician and the senior medical resident as well as the patient and families. This being said, medical students aren't present during the interprofessional bullet rounds which means they are often times not privy to the information being discussed.

Building on my concerns with the quality and attention payed to boundary objects in relation to patient education in this setting is the ignored problem of *info(r)mediation*. Given the number of people and boundary objects involved in patient education in the IMIU setting, *infomediation* can be assumed to be a near-constant. By ignoring *info(r)mediation*, the valence of the *infomediation* and how patients and families take up the information and transform it, appears to be left a lot to chance alone. Whereas in some contexts like surgery, there have been some *info(r)mediation* studies looking at what works better, there are no studies looking at that in this type of complex setting. I have explored the goals and utilization of PODS and I have shown that it is not working adequately, or as it was intended to. Further research may study what *info(r)mediation* does happen and how these settings can use PODS to ensure a more consistent uptake of the intended learning. For example, one of the most significant medical errors that

happen at the time of discharge is related to errors in the discharge medication prescription (Shah, Hough, & Jani, 2020) If an ongoing medication is entered incorrectly into the medical record, it may be flagged incorrectly as a stop or start when there has in fact been no change made. A proper PODS process would ensure that, at the time of discharge, the medications on the medical record are correctly reconciled with the patient's understanding of their own medications to ensure that everyone has correct and consistent information. An *info(r)mediation* approach focused on exploring how to best capture this for patients and their families would be a good place to ensure that the *infomediation* that arises does not lead or contribute to these errors. Rather it would lead to the appropriate behaviour change, which is reviewing medications with the pharmacist, ensuring that stopped medications are taken away and medications are taken up effectively.

While not specifically the focus of my study, the issue of patient medication education at the time of discharge is a perfect example of an opportunity to study the difference between *infomediation* and *info(r)mediation*. When patients receive a medication list indicating changes at the time of discharge, to what extent does it serve to adequately help them understand how to navigate their medications when they get home? One example in the literature addresses whether there is a difference between patients bringing a list of medications and bringing their pill bottles to the pharmacist to ensure they are relabelling any duplicate medications (Meyer et al., 2012). Some patients may not realize that their new perscription may be the same as their old perscription; patients often end up taking two of the exact same pill with a different trade name. While I did not write about this explicitly in the article, a perfect example observed relates to how patients are educated at discharge around medication changes (Shah, Hough, & Jani, 2020). Ignoring *info(r)mediation* allows physicians and nurses to simply hand patients a list of medication changes without confirming that they know how to act to prevent medication errors, which are known to be major source of morbitity and mortality (Christensen, & Lundh, 2016). By contrast, if an *info(r)mediation* approach was used, we would study different ways of conveying this information, and observe the impact the medication education has on the outcome of patients ability to navigate their medications once they get home. We need to explore which strategies will prevent these medication

errors; it is not sufficient to simply convey the written information to patients and use a teach-back method at the time of dicharge to ensure a patient has understood. The goal of an *info(r)mediation* approach is not merely to educate, but how we use this education to change a patient's behaviour. It seems as though in patient education in the IMIU we ha've ignored all of the behaviour change elements and we've put all the onus on patients. There is an underlying assumption that patients are capable of taking the information we give them and are able to transform it, in other words infomediating the information in a successful way.

PODS has never really functioned effectively as boundary object to achieve *info(r)mediation* because multiple members of the team don't have the opportunity to contribute to it. Even if they do get the chance, not all take up that opportunity. In addition, the people who actually deliver the PODS with the patient go over it at a time when the patient is often not receptive, the PODS document is not always self-evident and the person who needs the information (such as the family advocate) isn't always present. Ultimately, PODS does not achieve *info(r)mediation* consistently.

For patients who required support or who were less proactive during their stay, family advocates became essential *info(r)mediators* to the success of patient education and support (Wathen et al., 2008, p.6). Though the health care providers conveyed the inevitable *infomediation* transformation of information through clinical updates and documentation, the family advocates were the human mediators that enabled a change in the patient's behaviour or actions (Wathen et al., 2008, p.6). Education and decision making often overlapped in interactions between the health care providers and the patient's family advocates, resulting in negotiation between them and the health care providers. For example:

> *Field note: **Att 3** needed to take a listen to **Pt 40's** heart, but he wasn't taking proper breathes. The family advocate went directly in front of the patient's field of vision and started mimicking deep breathes with hand gestures, and Pt 40 followed that action.*

> *Field note: **Pt 37** had very low energy and seemed to be quite confused when **R2** walked into her room. While the R2 was presenting CT results to the patient and the FA*

*present, Pt 37 interrupted and said, "Tell this to my daughter (pointing to the FA), she'll understand".*

In summary, I observed many instances in which PODS, people, and patient charts, could all function as boundary objects but did so imperfectly, in part because they ignored the important role they were supposed to play in info(r)mediation. There are many potential boundary objects that need to be attended to, and in particular, they need to be attended to in relation to info(r)mediation. Throughout this study, I learnt a lot about PODS and the role it plays within the IMIU setting. Though it failed as an effective boundary object in support of patient education, this leads me to think in new ways about boundary objects and how they can be designed and utilized in this type of setting. For example, it may be that discharge education tools can never serve as a proper boundary object in this complex setting. That being said, I believe there are two ways in which humans can take on the role of a boundary object. Firstly, it may be that the patients themselves function as boundary objects since their body is the component that every member focuses on in a collaborative manner. However, this does not help us with patient education. Another way to approach this would be to consider having a designated patient educator. Regardless of clinical training or background, it is possible that if there was someone on the care teams who had a specific patient education role, they themselves could potentially function as the boundary object. PODS serves as a passive boundary object in a complex health care setting, as individual health care providers must go into the PODS and add certain components. However, this type of setting might require a more active boundary object that seeks to put patient education at the forefront when interacting with all the members of the care team and their patients.

## 3.3    Discussion and conclusions

### 3.3.1 Literature review gaps

In Chapter 1, I identified five themes that demonstrated the gaps I found in the literature. This section will serve as a reminder of these gaps and will briefly state what this study has contributed to each.

The first theme identified was patient complexity, which is recognized within the setting of internal medicine (Vogeli et al., 2007). However, there is limited research that has examined how patient education is enacted with complex patients, and my study was able to give a glimpse of what that enactment looked like. I recognize that no improvements to patient education will change the level of complexity of the patient's comorbidities. Patients with multi-comorbidities generate complex challenges for clinical care (Fortin et al., 2006) on their own, which means that patient education practices will not diminish the level of patient complexity. The second identified theme was around interprofessional teams: in recent years, research has explored the concept of "teamwork" (Greysen et al., 2012; Wong et al., 2011) from the perspective of various health care professionals. Nonetheless, little attention has been given to research that focuses on examining the range of factors that influence interprofessional patient education. My study was able to explore the varying roles, understandings and perspectives of patient education in an interprofessional team context. I found that the structure and the scope of the health care provider team was so complex that simple solutions to improve patient education (such as PODS) may not be sufficient in this environment. However, heath care providers could benefit by integrating the role of family advocates (Lambert & Loiselle, 2007, p. 1013) and acknowledging that they sometimes act as recipients of patient education, and sometimes as providers of information to the health care team. The third gap identified was that the literature tends to take a health care provider centered view on patient education needs. As Lee & Garvin, (2003) have found, effective patient education consists of more than just telling patients what to do. My study methodology enabled the co-construction of patient education findings from both the patient's and the health care provider's perspective. The fourth gap identified showcased that the literature focuses on a single event of patient education in hospital, emphasizing the point of discharge (Pinelli et al., 2017). I believe one of the most significant contributions this study adds to literature is that theoretical processes and frameworks such as RED (Jack et al., 2013) and quality improvements such as PODS still conceptualizes a patient's educational needs at a specific point in time. In reality, as my study demonstrated, there are multiple moments of patient education that occur and that are required to occur, and the educational needs change and vary throughout a patient's stay. Finally, the last gap

identified how the literature rarely considers the sociotechnical interrelationships among people and tools (Jensen & Kushniruk (2016); Keshet et al., 2013. My study has contributed to sociotechnical interrelationships by recognizing that a boundary object in theory doesn't always work as a boundary object in practice.

## 3.3.2 Methodological reflections and limitations

Throughout the data collection process, this CGT observational study did not come without its challenges. Initially, I went into the setting with an idea of how the field interviews would unfold, however they proved to be quite difficult. Health care providers were often in a rush and didn't necessarily have time to explain the rationale behind their actions. Residents and senior residents, specifically, would often have a heavy caseload and an elaborate list of patients to visit within a specific time frame. This resulted in many instances where conversations between myself and the resident I was shadowing for the day were quite brief and occurred while we were running from one patient to another.

Another challenge was the variability of attending physician interaction styles (Goldszmidt et al., 2015). Some attendings prioritized a learning environment for trainees and others did not. My direct observations therefore ranged in depth and degree of access provided from team to team based on who was the supervising attending. Some were more open to questions from me, and others were not.

A further challenge I did not anticipate was working around the lucidity of patients. Many patients on the IMIU had some form of cognitive impairment in addition to their other comorbidities. This made it quite difficult to interview patients at times. Moreover, occasionally I purposefully selected health care providers to tag along with based on the patients they were looking after as I wanted to interview those patients. However, many times when visiting the patients, they were asleep. I often felt as though this was a missed opportunity to gain rich insights, which meant that I had to spend more time in the field in order to choose other opportunities for key informants to contribute to my research.

Finally, the presence of family advocates occurred quite spontaneously. As previously mentioned, family advocates did not have a set schedule and came to visit at varying times during the day and across multiple days of the week. I initially had the assumption that family advocates would be present more often than not during a patient's stay. However, this was not the case, and including them in direct observations and field interviews was a lot more challenging than I anticipated.

Through all of these challenges with the data collection, I refined my methods over time to respond to the nature of this hectic environment. I did this by acknowledging the importance of the notion of timing. Most of the challenges that occurred centered around the timing of interactions or lack thereof. I realized that more often than not, there isn't a perfect time and/or place to ask health care providers insightful questions. Since their interactions are so fast paced, they move quickly from one patient to another. Therefore, I focused less on waiting for the most optimal time for questioning (in a private room, sitting down with all their attention focused on the questions at hand) and engaged in spontaneous conversations as they arose in order to gain valuable contextual insight. To overcome differences in observational field notes depending on the amount of access supervisors allowed, I consistently wrote reflexive memos in order to capture my positionality and my role in this setting. In terms of lucidity of patients and presence of family advocates, I had to accept that this is something that was out of my control. Once I realized that, I would do my best to try and capture the moments with the selected patients and family advocates, and if this didn't work to my advantage, I would move on to find other key informants that could help me gain insight. I would try to re-visit some of the patients and family advocates that were not present during my initial encounter. However, I needed to acknowledge that trying to collect data from my originally intended patients and family advocates would take up much of my time and that by doing so, I would be missing other PE moments that occurred simultaneously. Therefore, acknowledging and refining the way in which I conducted my data collection throughout the study led me to gain some rich insights throughout the research project.

The limitations I identified in Chapter 2 show how I recognized that my understanding of patient education in an IMIU was incomplete. I was only one researcher conducting the

data collection, and in doing so, I acknowledge that not all patient education moments were observed. The moments I was able to observe provided merely a glimpse of the many patient education moments that occurred in this setting. However, as the goal was to gain an overarching understanding of the enactment of patient education, I knew I wouldn't be able to account for all the moments that occurred during the time I was in the IMIU.

Additionally, while I did attempt to observe the presentation of PODS and other educational materials, I was not able to identify the ways in which they were or were not taken up after discharge. Though I did observe some occasions where the PODS was not useful in the moment that it was presented, I am aware that I cannot speak to the role it may have once the patient has been discharged; whether patients and their family advocates use the information in the PODS, if it is useful at home or how they might act on it.

Ultimately, consistent with a constructivist grounded theory methodology, I acknowledge that the unravelling of the patient education moments of interprofessional collaboration is my interpretation. The purpose of this study was not to make these findings generalizable or transferable, rather it offers rich insights that could be potentially taken up by others to explore their own contexts and gives an in-depth perspective into the nature of the inpatient setting.

### 3.3.3 Implications for practice and education

The purpose of this study was to understand the overarching enactment of patient education in an IMIU setting. Throughout the process of conducting this study, I believe the findings demonstrate a few ways in which this research will be useful in informing practice and education through involving multiple members in research, considering the development of quality improvement initiatives, taking into account health information science concepts, and personal takeaways.

### 3.3.3.1    Problems with an everchanging clinical team

One of the things that became evident early in the study was the extent to which the medical students and residents on the teams had little understanding of the role played by each of the interprofessional members on the team and how best to interact with them. Reinforced by a medical student's perspective, *"there is just so much overlap between the HC/SW/PCF/OT roles" MS 3*. Even though the patient care facilitator played a pivotal role in supporting these interactions, the trainees persistently throughout the rotation appeared to have misunderstandings about what they could get, how they could function and where they could go. My findings suggest that more work still needs to be done to ensure that junior physician team members understand better how to involve and interact together with the interprofessional members. The IMIU offers lectures at certain times on interprofessional themes. However, medical students and residents don't always show up or these themes don't necessarily feel relevant at the time. The context is too complex to prepare them for it in advance. My findings would suggest that without addressing the understanding of what each person does and how best to interact together to support patient care, it will be difficult for newcomers to succeed.

### 3.3.3.2    Improving the quality of patient education

PODS is an interesting and good first step for the IMIU that has taken it up, but more work clearly needs to be done. Programs such as the re-engineered discharge process appear to be helpful and may have had more success in other settings because of some of the key features that are associated with them including a specific discharge educator. Most programs for enhancing patient education do not provide specific guidance or tools on how to ensure that patients' primary concerns, priorities, and preferences are factored into their treatment (Stacey et al., 2017; Van Veet et al., 2015). My findings show that conventional PE topics such as *"what is my health problem?", "what do I need to do?" and "why do I need to do this?"* (Byrd & Thompson, 2008) are not necessarily top of mind for all patients. Going forward, it is important to remember that the type of education patients need varies at different times during the stay. Early on, the patients and families need to be oriented to how the IMIU works, and what will be happening during their stay. During the stay, team members have to introduce themselves to patients and

families in order for them to become familiar with their role and how best to engage with the care team. Since patients were not necessarily receptive to education or did not want to engage at the time PODS was given, PODS might not improve patient education even if all components were conducted properly by the right people. This is something to be considered when thinking of the development and design tools for quality improvement initiatives. Asking questions such as: what is the goal of this tool? Who is the target of this education? What types of questions/concerns will resonate the most with patients? When is the right time for them to receive this education? These types of questions are needed as policy makers contribute to quality improvement initiatives.

### 3.3.3.3    Knowledge translation

The field of health information science (HIS) focuses on utilizing data and/or information in order to make better informed decisions and improve patient outcomes. HIS research focuses on fundamental health and health care concepts such as; public health, health policy/clinical health care, knowledge translation, knowledge organization management, patient and professional information seeking behaviour, and information/ethic policy. Through this lens, there are multiple gaps between evidence and decision-making that occur at all levels of health care, including those of patients, healthcare professionals and policymakers (Straus, Tetroe, & Graham, 2009). As this study's findings have demonstrated, there are many gaps related to patient education that contributed to effective and unsuccessful educational moments. Though this study provides valuable evidence from a clinical environment, it is not enough for the provision of optimal care without effective knowledge translation.  Knowledge translation is characterized as the methods used for closing the gaps from knowledge to practice, also known as the "know-do gap" between researchers and research users (Kothari & Wathen, 2013). Formally, knowledge translation is defined by the Canadian Institutes of Health Research as "a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system" (Straus, Tetroe, & Graham, 2009).

However, increasing "recognition of these gaps in translation knowledge to action has led to efforts to change behaviour, practices and policy" (Straus, Tetroe, & Graham, 2009). As noted by Straus & colleagues, changing behaviour is a complex process requiring the evaluation of an entire health care organization. As described in the previous chapters of this thesis, the notion of complexity characterizes many contextual and individualistic factors associated to the IMIU setting. Davis et al (2003) express that the evaluation of an entire health care organization includes the identification of barriers to change (e.g., lack of integrated health information systems) and targets all those involved in making decisions.

As indicated in the section above, addressing the issue of patient education and improving it in this context is not offered by a single solution. For this reason, my findings are not sufficient to simply to be translated; rather they provide a better understanding of the complexity of what any knowledge translation efforts need to address in order to move things forward. I cannot state that this study provides a theoretical framework or guidelines to be considered as specific solutions for closing the gaps from knowledge to practice. I believe that the ideals of optimal patient education are impossible to reach in the internal medicine setting due to the majority of barriers being structural and systemic. Without major changes at these levels, I do not think that effective patient education can be achieved. Nevertheless, this research identified the multiple barriers that need to be overcome and recognizes how complicated and complex the enactment of patient education can be. Though there is a need for improvement, it is definitely not an easy fix.

### 3.3.3.4    Personal takeaways

This entire research process has enabled me to gain the most valuable insights into the academic and clinical world. As I leave Western University to start my journey into medical school in September, these past two years have truly opened my eyes to the many possibilities academia has to offer in the clinical environment. I have gained an enriching experience from a program that draws expertise from both the Health Sciences and Information and Media studies faculties. This has contributed to my conceptual understanding of the inpatient setting. Throughout this journey, I have come up with my

own takeaways for how this thesis has helped me think about what medical students need to learn and what I need to think about from an HIS perspective as a future physician.

The first is that as medical students we must recognize the importance of interprofessional collaboration. I have seen first-hand how interprofessional collaboration is crucial in a hospital setting. Though I focused on its impact on aspects of patient education, it's essential as health care providers face a number of challenges such as "complexity of clinical practice, high variation in clinical demand, ever-changing teams and heavy workloads" (Muller-Juge et al., 2013). I believe that I will cultivate a new mentality when I am learning in a small or a large group with other health care providers. This thesis has taught me that interprofessional education specifically must foster a shared vision and understanding of every member's role and take into account the boundaries and underlying culture of each profession.

Secondly, without this research experience, I would have never realised how many aspects in medical education are not found in a textbook. I had an idea of what to expect when entering the field, and while general notions of patient education were similar, there were many others that I did not anticipate on encountering based off of the literature I had read. For example, my most surprising finding was the various types of concerns patients had at different times during their stay. Within the literature, I read about the concerns that patients most likely had during a hospital stay. However, for the most part, these did not line up with what I found in this IMIU setting. Therefore, when I will be observing and performing patient encounters in various settings, I will remind myself of this study to make sure that the educational components enforced by textbooks and lectures are not the only components I keep in mind while addressing patients during an encounter.

In addition to this, I will also make an effort to try and include family members, caregivers and/or family advocates to the fullest extent. I have observed how they not only provide emotional support but proved to be a key informant to the care team. I will be keeping this in mind during clinical rounds by engaging with the family advocates and considering their perspective.

Finally, as I will be navigating my way through medical school and my career as a future physician, I believe my most significant takeaway will simply be to remember to listen. I believe this research experience has proven to me how powerful and effective actively listening and observing can be. Though I know I will be extremely busy and pulled in many directions, I truly believe that taking a step back to listen to others, to observe the surroundings and appreciate other points of view, will make achieving efficient patient and care team encounters more attainable. At the end of the day, I have chosen this path because I want to help people, and I have seen firsthand that immeasurable healing and collaboration takes place when someone stops, sits down, and listens.

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# Appendices

## Appendix A: List of acronyms

IMIU: internal medicine inpatient unit

PE: patient education

HCP: health care provider

RED: re-engineered discharge process

PODS: patient oriented discharge summary

CGT: constructivist grounded theory

# Appendix B: Interview prompts

While a CGT observational study may not require an interview "script", there are certain probe questions that helped me when interviewing patients and health care providers after an observation session.

**For patients:**
o What do you understand about what brought you into the hospital?
o [after an interaction with a health-care provider] How do you feel that interaction went? Did you learn anything new?
o Are you aware of which team members are looking after you for which reason?
o Is there a tool or a person that has helped you understand more fully what is going on?
o Did you take away the same information that was presented to you during the discharge process?
o Have all your questions been answered?

**For health care providers:**
o Did you feel the patient fully understood what was going on during that interaction?
o Would you consider that interaction to be one of "patient education"?
o Is there a tool or a person that has helped you understand more fully what is going on?
o Do you feel that discharge summary accurately represents what the patient should have taken away from their hospital stay?
o Who is responsible for conducting the discharge summary process and who answers any questions the patient may have?

# Appendix C: Letter of information and consent form
# (patients)

**1. Invitation to Participate:** You are being invited to consider participating in a study exploring who the different health care providers for patients are because you are an individual with complex health care needs and we are interested in learning about the care as well as the education you receive and the individuals who provide that care and education. This study is being conducted by Dr. Mark Goldszmidt of the Centre for Education Research & Innovation at the Schulich School of Medicine & Dentistry.

**2. Why is This Study Being Done**? We are interested in studying patient's education needs as well as how care for patients with more than one disease or condition is delivered and who delivers it. As a result of this research, we hope to learn about the network of doctors patients access for their health care and educational needs. This may help us design future research and make improvements in health care delivery.

**3. How Long Will You be in This Study?** You are invited to accompany the person you care for in a 30-minute to 1-hour long interview during their stay in the hospital. After the interview, you will not be required to have any further participation in the study.

**4. What Are the Study Procedures?** This study will take place at London Health Sciences Centre (LHSC)-University Hospital and LHSC-Victoria Hospital. During this study, a Research Assistant will conduct a brief 30 minute to 1-hour long interview with patients and their caregivers in the room. The interview will ask the person you care for questions about the health issues and which doctors provide health care and help to manage their health. In addition to this, you will be asked about your educational needs regarding your hospital stay. In order to capture the information you provide during the interview, we would like to audio-record these sessions. You will not be included in this study if you don't want to be audio-recorded. Your name will not be identified with any comments you make and potentially identifying information will be removed when the audio-recording is transcribed into words. If you wish to withdraw your information at a later date, you may do so by contacting the Principal Investigator (Dr. Goldszmidt) and identifying yourself with the date and time of your interview, as we will not retain your name. The data will be de-identified to make sure that others cannot identify you, and you will be referred to only by number (e.g. interviewee 1). Approximately 60 participants will take part in this study.

**5. What are the Risks and Harms of Participating in This Study?** This study involves minimal risks. At the individual level for participants in this study, the largest risk would involve feeling self-conscious about being interviewed and potentially disclosing sensitive health information of the person you care for.

**6. What are the Benefits of Participating in This Study?** The most likely benefit would be an increased understanding of how patients and physicians manage health issues after discharge from hospital and if the health care team is meeting patients'

education standards. With this increased understanding, we hope to inform quality improvement projects to provide better in-hospital and post-discharge support for patients.

**7. Can Participants Choose to Leave this Study?** You can decide whether or not you would like to participate in this study. Your decision whether or not to participate in this study will have no impact on your health care. If you decide to withdraw from the study, you have the right to request withdrawal of information collected about you. If you wish to have your information removed please let the researcher know and we will do so if it is feasible. NOTE: Once the data has been analyzed and the study has been published, we will not be able to withdraw your information.

**8. How Will Participants' Information be Kept Confidential?** All data, including the transcribed audio-recordings, will be stored on a password-protected, secured network server for fifteen years. Only the researchers listed above will have access to the study's records. A list linking your participant number with your name will be kept by the researcher in a secure place, separate from our study file. Your name will not be associated with the results obtained from this study. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research. Lawson's Quality Assurance Evaluation Program may also access study data for quality assurance purposes.

**9. Are Participants Compensated to be in This Study?** You will not be compensated for your participation.

**10. What Are the Rights of the Participants?** Your participation in this study is voluntary. You may decide not to be in this study. Even if you agree to participate you have the right to not answer individual questions or to remove yourself from the study at any time. If you choose not to participate or to leave the study at any time it will have no effect on your health care. We will give you new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

**11. Whom do Participants Contact for Questions?** If you have questions about this research study please contact the Principal Investigator Dr. Mark Goldszmidt,. If you have any questions/concerns about your rights as a research participant or the conduct of this study, please contact: St. Joseph's Health Care London Patient Relations Consultant.

**This letter is yours to keep for future reference.**

**Project Title:** Clinical Teaching Unit (CTU) Communication Research Project

**Document Title:** Letter of Information

**Principal Investigator:**
Dr. Mark Goldszmidt, MD, PhD
Centre for Education Research & Innovation
Schulich School of Medicine & Dentistry
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Faculty of Information and Media Studies
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**Collaborator:**
Talia Di Marco, MHIS candidate
Graduate Student, Researcher
Faculty of Information and Media Studies, Faculty of Health Sciences
Western University

I have read the Letter of Information (have had the nature of the study explained to me) and I agree to participate. All questions have been answered to my satisfaction.

I agree to be audio-recorded in this research.

☐ **YES** ☐ **NO**

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research.

☐ **YES** ☐ **NO**

I consent to the research team accessing my patient chart.

☐ **YES** ☐ **NO**

| | | |
|---|---|---|
| Print Name of Participant | Signature | *Date (DD-MMM-YYY)* |

My signature means that I have explained the study to the participant named above. I have answered all questions.

| | | |
|---|---|---|
| Print Name of Person | Signature | *Date (DD-MMM-YYY)* |

# Appendix D: Letter of information and consent form (caregivers)

**1. Invitation to Participate:** You are being invited to consider participating in a study exploring who the different health care providers for patients are because as a caregiver you are involved in caring for an individual with complex health care needs and we are interested in learning about the care as well as the education they receive and the individuals who provide that care and education. This study is being conducted by Dr. Mark Goldszmidt of the Centre for Education Research & Innovation at the Schulich School of Medicine & Dentistry.

**2. Why is This Study Being Done**? We are interested in studying patient's education needs as well as how care for patients with more than one disease or condition is delivered and who delivers it. As a result of this research, we hope to learn about the network of doctors patients access for their health care and educational needs. This may help us design future research and make improvements in health care delivery.

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**5. What are the Risks and Harms of Participating in This Study?** This study involves minimal risks. At the individual level for participants in this study, the largest risk would involve feeling self-conscious about being interviewed and potentially disclosing sensitive health information of the person you care for.

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issues after discharge from hospital and if the health care team is meeting patients' education standards. With this increased understanding, we hope to inform quality improvement projects to provide better in-hospital and post-discharge support for patients.

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**8. How Will Participants' Information be Kept Confidential?** All data, including the transcribed audio-recordings, will be stored on a password-protected, secured network server for fifteen years. Only the researchers listed above will have access to the study's records. A list linking your participant number with your name will be kept by the researcher in a secure place, separate from our study file. Your name will not be associated with the results obtained from this study. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research. Lawson's Quality Assurance Evaluation Program may also access study data for quality assurance purposes.

**9. Are Participants Compensated to be in This Study?** You will not be compensated for your participation.

**10. What Are the Rights of the Participants?** Your participation in this study is voluntary. You may decide not to be in this study. Even if you agree to participate you have the right to not answer individual questions or to remove yourself from the study at any time. If you choose not to participate or to leave the study at any time it will have no effect on your health care. We will give you new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

**11. Whom do Participants Contact for Questions?** If you have questions about this research study please contact the Principal Investigator Dr. Mark Goldszmidt. If you have any questions/concerns about your rights as a research participant or the conduct of this study, please contact: St. Joseph's Health Care London Patient Relations Consultant.

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Faculty of Information and Media Studies, Faculty of Health Sciences
Western University

I have read the Letter of Information (have had the nature of the study explained to me) and I agree to participate. All questions have been answered to my satisfaction.

I agree to be audio-recorded in this research.

☐ **YES** ☐ **NO**

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research.

☐ **YES** ☐ **NO**

| _____ | _____ | _____ |
|:---:|:---:|:---:|
| Print Name of Participant | Signature | _Date (DD-MMM-YYY)_ |

My signature means that I have explained the study to the participant named above. I have answered all questions.

| _____ | _____ | _____ |
|:---:|:---:|:---:|
| Print Name of Person | Signature | _Date (DD-MMM-YYY)_ |

# Appendix E: Letter of information and consent form (health care providers)

**1. Invitation to Participate:** You are being invited to consider participating in a study exploring who the different health care providers for patients are because as a health care provider, you are directly involved in caring for patients with complex health care needs and we are interested in learning about the care as well as the education you provide. This study is being conducted by Dr. Mark Goldszmidt of the Centre for Education Research & Innovation at the Schulich School of Medicine & Dentistry.

**2. Why is This Study Being Done**? We are interested in studying patient's education needs as well as how care for patients with more than one disease or condition is delivered and who delivers it. As a result of this research, we hope to learn about the network of doctors patients access for their health care and educational needs. This may help us design future research and make improvements in health care delivery.

**3. How Long Will You be in This Study?** You are invited to accompany the person you care for in a 30-minute to 1-hour long interview during their stay in the hospital. After the interview, you will not be required to have any further participation in the study.

**4. What Are the Study Procedures?** This study will take place at London Health Sciences Centre (LHSC)-University Hospital and LHSC-Victoria Hospital. During this study, a Research Assistant will conduct a brief 30 minute to 1-hour long interview with patients and their caregivers in the room. The interview will ask the person you care for questions about the health issues and which doctors provide health care and help to manage their health. In addition to this, you will be asked about your educational needs regarding your hospital stay. In order to capture the information you provide during the interview, we would like to audio-record these sessions. You will not be included in this study if you don't want to be audio-recorded. Your name will not be identified with any comments you make and potentially identifying information will be removed when the audio-recording is transcribed into words. If you wish to withdraw your information at a later date, you may do so by contacting the Principal Investigator (Dr. Goldszmidt) and identifying yourself with the date and time of your interview, as we will not retain your name. The data will be de-identified to make sure that others cannot identify you, and you will be referred to only by number (e.g. interviewee 1). Approximately 60 participants will take part in this study.

**5. What are the Risks and Harms of Participating in This Study?** This study involves minimal risks. At the individual level for participants in this study, the largest risk would involve feeling self-conscious about being interviewed and potentially disclosing sensitive health information of the person you care for.

**6. What are the Benefits of Participating in This Study?** The most likely benefit would be an increased understanding of how patients and physicians manage health issues after discharge from hospital and if the health care team is meeting patients'

education standards. With this increased understanding, we hope to inform quality improvement projects to provide better in-hospital and post-discharge support for patients.

**7. Can Participants Choose to Leave this Study?** You can decide whether or not you would like to participate in this study. Your decision whether or not to participate in this study will have no impact on your health care. If you decide to withdraw from the study, you have the right to request withdrawal of information collected about you. If you wish to have your information removed please let the researcher know and we will do so if it is feasible. NOTE: Once the data has been analyzed and the study has been published, we will not be able to withdraw your information.

**8. How Will Participants' Information be Kept Confidential?** All data, including the transcribed audio-recordings, will be stored on a password-protected, secured network server for fifteen years.  Only the researchers listed above will have access to the study's records. A list linking your participant number with your name will be kept by the researcher in a secure place, separate from our study file. Your name will not be associated with the results obtained from this study. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research. Lawson's Quality Assurance Evaluation Program may also access study data for quality assurance purposes.

**9. Are Participants Compensated to be in This Study?** You will not be compensated for your participation.

**10. What Are the Rights of the Participants?** Your participation in this study is voluntary. You may decide not to be in this study.  Even if you agree to participate you have the right to not answer individual questions or to remove yourself from the study at any time.  If you choose not to participate or to leave the study at any time it will have no effect on your health care. We will give you new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

**11. Whom do Participants Contact for Questions?** If you have questions about this research study please contact the Principal Investigator Dr. Mark Goldszmidt. If you have any questions/concerns about your rights as a research participant or the conduct of this study, please contact: St. Joseph's Health Care London Patient Relations Consultant.

**This letter is yours to keep for future reference.**

**Project Title:** Clinical Teaching Unit (CTU) Communication Research Project

**Document Title:** Letter of Information

**Principal Investigator:**
Dr. Mark Goldszmidt, MD, PhD
Centre for Education Research & Innovation
Schulich School of Medicine & Dentistry
Western University

**Collaborator:**
Dr. Pamela McKenzie, PhD
Associate Professor
Faculty of Information and Media Studies
Western University

**Collaborator:**
Talia Di Marco, MHIS candidate
Graduate Student, Researcher
Faculty of Information and Media Studies, Faculty of Health Sciences
Western University

I have read the Letter of Information (have had the nature of the study explained to me) and I agree to participate. All questions have been answered to my satisfaction.

I agree to be audio-recorded in this research.

☐ **YES** ☐ **NO**

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research.

☐ **YES** ☐ **NO**

| | | |
|---|---|---|
| Print Name of Participant | Signature | *Date (DD-MMM-YYY)* |

My signature means that I have explained the study to the participant named above. I have answered all questions.

| | | |
|---|---|---|
| Print Name of Person | Signature | *Date (DD-MMM-YYY)* |

# Appendix E: Ethics approval forms



**Date:** 24 July 2019

**To:** Dr. Mark Goldszmidt

**Project ID:** 6822

**Study Title:** CTU Communication Research Project - 16823E

**Reference Number/ID:** N/A

**Application Type:** HSREB Amendment Form

**Review Type:** Delegated

**Full Board Reporting Date:** August 6, 2019

**Date Approval Issued:** 24/Jul/2019

**REB Approval Expiry Date:** 08/Feb/2020

Dear Dr. Mark Goldszmidt ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

**Documents Approved:**

| Document Name | Document Type | Document Date |
|---|---|---|
| Talia Information Letter & Consent Form- Caregiver (1) | Consent Form | 26/Jun/2019 |
| Talia Information Letter & Consent Form- Patients (2) | Consent Form | 26/Jun/2019 |
| Western Protocol 6822 | Protocol | 16/Jul/2019 |

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Karen Gopaul, Ethics Officer on behalf of Dr. Philip Jones, HSREB Vice-Chair

*Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).*

**Date:** 11 October 2019

**To:** Dr. Mark Goldszmidt

**Project ID:** 6822

**Study Title:** CTU Communication Research Project – 16823E

**Reference Number/ID:** N/A

**Application Type:** HSREB Amendment Form

**Review Type:** Delegated

**Full Board Reporting Date:** November 5, 2019

**Date Approval Issued:** 11/Oct/2019

**REB Approval Expiry Date:** 08/Feb/2020

Dear Dr. Mark Goldszmidt ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

**Documents Approved:**

| Document Name | Document Type | Document Date |
|---|---|---|
| [Clean 1] Talia Information Letter & Consent Form- Caregiver | Consent Form | 04/Oct/2019 |
| [Clean 2] Talia Information Letter & Consent Form- Patients | Consent Form | 04/Oct/2019 |
| [Clean 3]- Talia Information Letter & Consent Form- Health Care Provider | Consent Form | 04/Oct/2019 |

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Karen Gopaul, Ethics Officer on behalf of Dr. Philip Jones, HSREB Vice-Chair

*Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).*

# Appendix G: Table 3 extension

| 1. Effective education moments | a. Open lines of communication across the team | *Field note: **Att 1**[8] stated to the medical team during the morning rounds that it is more beneficial to explain to the nurses why they are doing what they're doing. If the nurses fully understand it, they be more inclined to do it and they will be capable of answering more patient questions.* |
|---|---|---|
| | b. Presence of all relevant team members | ***Pt 16** disclosed "I am here for a reason; you guys are here (pointing to **HCPs**) my family is here, and I want to get better".* |
| | c. Presence and engagement of patient and/or advocate | *Field note: **Pt 37** had very low energy and seemed to be quite confused when **R2** walked into her room. While the R2 was presenting CT results to the patient and the **FA** present, Pt 37 interrupted and said, "Tell this to my daughter (pointing to the FA), she'll understand".*<br><br>*Field note: **Att 3** needed to take a listen to **Pt 40's** heart, but he wasn't taking proper breathes. The family advocate went directly in front of the patient's field of vision and started mimicking deep breathes with hand gestures, and Pt 40 followed that action.* |

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[8] Legend of pseudonyms: Att=Attending, FA= Family advocate, HC= Home care coordinator, HCP= Health care provider, MS= Medical student, N= Nurse, OT= Occupational therapist, Pt= Patient, PCF= Patient care facilitator, PH= Pharmacist, PT= Physiotherapist, RD= Registered dietician, R= Resident, SW= Social worker

# Appendix H: Table 4 extension

| Concerns | Patient and family concerns | HCP concerns |
|---|---|---|
| 1. Concerns of daily living in hospital | a. <u>Hospital food</u><br>*"I need food to survive, real food […] I want a nice slice of pizza from the cafeteria"* **Pt 35**.<br>*"My mom is getting very tired of this bland diet… and her food is sometimes cold"* **CG 1.**<br><br>b. <u>Hospital atmosphere</u><br>*"There's just too many patients in this room… and there's always one that keeps us up at night"* **Pt 3.** | |
| 5. Other PE challenges identified only by HCPs | | c. <u>Proper referrals</u><br>**SW M** *expressed that:*<br>*"Particularly medical students and residents, they get very confused as to whose role is whose […] we don't get the right referrals a lot of the time from them"*<br><br>d. <u>Variability of attending styles</u><br>**PCF N** *mentioned: "I think forming relationships are hard between health care professionals and physician team members because of the frequent change in schedules".* |

# Curriculum Vitae

**Name:**              Talia Di Marco

**Post-secondary**     Laurentian University
**Education and**      Sudbury, Ontario, Canada
**Degrees:**           2014-2018 B.PHED.

                       The University of Western Ontario
                       London, Ontario, Canada
                       2018-2020 M.HIS.

**Related Work**       Teaching Assistant
**Experience**         The University of Western Ontario
                       2018-2020

                       Research assistant intern
                       Centre for Rural and Northern Heath Research (CRaNHR)
                       2016-2018