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Patient Perspectives on Transitions of Surgical Care: Examining the Complexities and Interdependencies of Care

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Abstract
This study examined a thematic network aimed at identifying experiences that influence patients’ outcomes (e.g., patients’ satisfaction, anxiety, and discharge readiness) in an effort to improve care transitions and reduce patient burden. We drew upon the Sociology and Complexity Science Toolkit to analyze themes derived from 61 semistructured, longitudinal interviews with 20 patients undergoing either a benign or malignant colorectal resection (three interviews per patient over a 30-day after hospital discharge). Thematic interdependencies illustrate how most outcomes of care are significantly influenced by two cascades identified as patients’ medical histories and home circumstances. Patients who reported previous medical or surgical histories also experienced less distress during the discharge process, whereas patients with no prior experiences reported more concerns and greater anxiety. Patient dissatisfactions and challenges were due in large part to the contrasts between hospital and home experiences. Our hybrid approach may inform patient-centered guidelines aimed at improving transitions of care among patients undergoing major surgery.

Keywords
patient perceptions; transitions of care; discharge process; surgical outcomes; complexity science; qualitative methods; northeastern US.

Introduction
Patient transitions between hospital and home settings are highly complex, involving multiple health care providers and points of care. When not managed optimally, this complexity results in poor patient experience, medical errors, complications, and unplanned hospital readmissions (Goodman, Fisher, & Chang, 2013; Naylor & Keating, 2008). High readmission rates result in substantial human and financial burdens and lead to provider penalties. In 2004, unplanned readmissions of Medicare patients in the United States cost the health care system an estimated US$17 billion (Jencks, Williams, & Coleman, 2009). Of these patients, 19% were readmitted to the hospital within 30 days after discharge. Inadequate care coordination may be responsible for US$25 to US$45 billion annually in wasteful spending on avoidable complications and unnecessary hospital readmissions (Burtin, 2012). Several transitional care models and interventions have been developed to help address these system deficiencies (Coleman, Parry, Chalmers, & Min, 2006; Goldfield et al., 2008; Kind, Smith, Frytak, & Finch, 2007; Ma, Coleman, Fish, Lin, & Kramer, 2004). Among patients undergoing colorectal resections, current models and quality improvement interventions assume linear and stable relationships between care processes and outcomes and associated intra- and postoperative complications such as bleeding and bowel injury (Kirchhoff, Clavien, & Hahnloser, 2010). We argue that linear approaches may not account for individual variation in patients’ self-care skills, social context, quality of their support systems, and ability and competence to manage stress associated with navigating the health care system.
system. The representation of care processes as stable and consistent over time is not accurate either. The evidence suggests that adherence to clinical guidelines, patient-provider communication skills, and availability of services vary among providers, by care site, and by day of the week (Coleman et al., 2006; Goldfield et al., 2008; Kind et al., 2007; Ma et al., 2004).

Questioning why existing interventions and policies have not been effective has drawn attention to patient-centered care and the dynamical and unpredictable nature of the health care system (Lipsitz, 2012; Plsek & Greenhalgh, 2001). This is especially important for patients undergoing colorectal resections as studies show considerable hospital-to-hospital variation in surgical outcomes (Ingraham et al., 2010). Improving outcomes for these patients requires that we increase the quality of multidisciplinary care in monitoring, treating, and preventing potential complications and conditions. Improving the quality of recovery in this patient group may depend on examining the unpredictable psychosocial factors that affect behavior from diagnosis to home recovery, including how postsurgical distress affects normal life functions and disrupts the daily activities of patients and their families (Avery et al., 2006; Department of Health, Western Australia, 2008). Therefore, examining patient perspectives through a complexity lens allows us to unpack the dynamic relationships between their experiences and contexts of care and, in turn, positions us to detect patient barriers and improve self-care skills.

Background

Recent literature has begun to explore health care delivery practices from the perspective of complex systems theory (Begun, Zimmerman, & Dooley, 2003; Litaker, Tomolo, Liberatore, Stange, & Aron, 2006; Plsek & Greenhalgh, 2001; Sturmberg, O’Halloran, & Martin, 2012). After all, health care delivery practices operate in very complex organizational environments and are, themselves, complex organizational forms. Complexity science suggests that the key to understanding global system behavior requires identifying patterns of relationships between the system’s agents (McDaniel, Lanham, & Anderson, 2009). For instance, health care delivery practices comprise networks of agents (e.g., doctors, nurses, social workers) and components (e.g., hospitals, rehabilitation units, clinics, patients’ homes) that interact nonlinearly on different scales. Examining these relationships offers fresh insight into the nature of complex organizational systems and several of their intrinsic properties, including nonlinear interactions, emergent self-organization, and micro-macro dynamics (McDaniel et al., 2009). Hence, efforts to improve health care practices for patients undergoing a colorectal resection would benefit from incorporating complexity science to address patient heterogeneity and the interconnections of different contexts and points of care.

While the concept of complexity in health care delivery may offer ways of going beyond the limits of reductionism, it is often defined in different ways. We use a complexity science framework to understand the variation of social practices within the health care delivery system among patients undergoing a colorectal resection. For the purposes of this research, “complexity” is defined as diverse relationships among patients’ experiences of their care and the systems within which that care is delivered; “adaptive” is defined as patients’ experiences associated with the adaptation or coping processes, including behavior modifications over time in response to various internal and external forces; and “systems” is defined as the contextual interdependencies between hospitals and patients’ homes (Begun et al., 2003; Brown, 2013). This research embraces these definitions via qualitative inquiry (Gilbert & Troitzsch, 2005; Johnson, 2013): We explore the nature of complexity from a qualitative perspective that focuses on the experiences of the patient (Agar, 2004; Gummesson, 2006; Sturmburg & Martin, 2013).

The goal of this study is to examine the surgical care pathway from the patient’s point of view to identify experiences and events that influence patient outcomes (e.g., a patient’s satisfaction, anxiety, and discharge readiness) in an effort to improve care transitions and reduce patient burden. The surgical care pathway is characterized by three profiles that include preoperative/inpatient settings, discharge from hospital, and follow-up care at home. We drew upon methods from social and complexity science to assemble and examine a network of themes using patient narratives (Geary & Schumacher, 2012; Martin & Sturmburg, 2013). We rely on a complexity-based ontology guided by patient narratives to examine patterns of experiences and events that emerge dynamically across multiple contexts and points of care. By weaving patient perceptions into a complexity science framework, new light is shed on ways to improve care management among patients undergoing colorectal resections and improve overall quality of care.

Participants

We recruited adult patients undergoing colon or rectal resection (either benign or malignant indication) at one of the largest academic medical centers in upstate New York between December 2013 and March 2014. These patients were scheduled to be discharged home with or without visiting nurse services. The advanced practice providers introduced the study to the patients in the hospital setting in the early postoperative period, days before patients...
were scheduled to be discharged to their homes. Those patients interested in participating were then introduced to the recruiting member of the research team, and an attending physician experienced in qualitative methods and interviewing, to establish a relationship with patients, further explain the study, and answer any questions. We collected written informed consent from patients prior to discharge. Institutional review board approval for the study was obtained prior to subject recruitment and any data collection (Research Subjects Review Board [RSRB] Approval 000049044). Participants who lacked the capacity to provide consent and those who needed a stay in a skilled nursing facility were excluded.

**Semistructured Interviews**

Semistructured interviews were used to gather data from patients concerning their experiences, including their perceptions of the quality of hospital staff and services, the discharge planning process, support systems, and their own home environments. Patients were interviewed over the phone on three occasions: the day following discharge, a week later after the first interview, and a month after discharge. Conducting multiple interviews allowed us to examine and compare the experiences of patients over time. All interviews were undertaken by the attending physician and recruiting member of the research team. The interviews were designed to ask broad questions with probes about patient experience and took about 15 to 30 minutes. Our probes were intended to obtain detailed information about patient experiences that could be linked to other themes. Sample probes in our areas of interest included the following: How has having surgery changed your day-to-day life? How have you adjusted? Tell me what it is like to go from being in the hospital to going home? Patients were offered a US$20 gift card after completing each interview. Questions were modified over the course of the study based on study findings to maximize the information attained. Each interview was audiotaped, transcribed, and reviewed for accuracy by a study team member prior to analysis.

**Method**

This research used the Sociology and Complexity Science (SACS) Toolkit, a new method for modeling complex systems that allows for the integration of multiple techniques, including qualitative methods (Castellani & Hafferty, 2009). As a hybrid method, it combines principles from SACS to assemble networks of a social system. To further validate bringing the SACS Toolkit to bear on our data, we integrated grounded theory (Brink et al., 2006), the Definitional Test of Complex Systems (DTCS; Castellani, Rajaram, Buckwalter, Ball, & Hafferty, 2015), and complex modeling and graphing techniques (Sturmburg, Churilov, & McDonnell, 2013).

Grounded theory was applied within the SACS Toolkit because it is designed to investigate complex multifaceted phenomena (Charmaz, 2003). The main purpose of grounded theory is theory building. As such, the model is neither exclusively inductive nor deductive, but rather combines both as a form of abductive reasoning (Timmermans & Tavory, 2012). Grounded theory is structured by three stages of analysis: open coding, axial coding, and selective coding (Strauss & Corbin, 1990). These steps are used to examine conceptual density, thematic interconnections, and higher order commonality among concepts presented in quadrants or axes. Similarly, the SACS Toolkit examines network density and defines interconnections as “... the process by which a network of attacking clusters becomes more densely connected” (Castellani & Hafferty, 2009, p. 203).

It has been argued that grounded theory does not account for noise and chaos in the data, and that it thus fails to recognize the embeddedness of information in large amounts of data (Allan, 2003; Olesen, 2007). The SACS Toolkit overcomes some of the limitations of grounded theory by using transitive inference to organize multilayered interactions between the embedded dimensions and levels of inquiry. Transitive inference is an essential feature in understanding how networks are structured (e.g., if A > B and B > C, then A > C). The SACS toolkit uses transitive inference via a six-step algorithm to operationalize folders of information and assemble networks of a given social system from the ground up (Castellani & Hafferty, 2009). The SACS assemblage process is theoretically grounded; therefore, its six-step algorithm uses deductive logic to translate theory and test research questions that either confirm or disconfirm a construct. Each step provides the basis for the next until cross-sectional snapshots of information within the network emerge, and the steps are repeated and revised until an identified model is established (Castellani & Hafferty, 2009). This algorithm is applicable to qualitative data, and similar attempts in qualitative inquiry exist. For instance, the illustrative method uses empty boxes to be filled with theoretical descriptions of data to inform a general model (Bonnell, 1980; Skocpol, 1984), and the successive approximation method allows for pattern matching across qualitative observations through a back-and-forth approach between data and abstract concepts (Mahoney, 2000).

The SACS toolkit was used in our study to examine a series of inductive and deductive research questions about patient narratives within and between three catalogs referred to as profiles (inpatient/hospital settings, discharge from hospital, and home environments). Similarly, Schutt (2006) uses inductive and deductive
approaches simultaneously in topics across the social sciences for examining thematic interconnections (Schutt, 2006). We found this approach to be useful in understanding differences, similarities, and specific situations among patient experiences.

The inductive approach was used to explore emerging themes within-and-between the three profiles. Sample inductive questions include the following: How do patients experience their hospital stay before discharge? How do patients experience the discharge process? What are patients’ expectations from the surgical team and their care providers? After mapping open codes within-and-between profiles, we applied a deductive approach to examine the general associations of clustered themes.

In the deductive approach, the SACS algorithm was used to operationalize common features and link different levels of phenomenological experiences. To illustrate, open codes to “anxiety,” “frustration,” and “worry” were cataloged under “emotion.” Thus, if the label code “emotion” was present, the deductive research question was then “Do patient emotions affect the process of communicating/making decisions with their A) doctors > B) > care team, and > C) care providers; where ‘>’ denotes greater linkage for decision making and support latitude among patients across profiles?” We define these thematic interconnections as links that cut across the three profiles connecting to other clustered themes and because they were the most repetitive dominant themes among participants. In our analysis, the deconstruction of quotes examined via SACS algorithm, which captured shared experiences among patients, was sufficient to illustrate an interconnection, or single quotes that were linked to other quotes mentioned at a later time during the interview process. The sum of themes across our three profiles produced a global model that we refer to as the transition of care model (TCM). This model represents a “moving” picture of the system’s dynamics that shape and constrain patient activity and experiences.

Within the fusion of the SACS Toolkit and grounded theory, we also used DTCS (Castellani & Hafferty, 2009; Castellani et al., 2015) as an attempt to examine if key system characteristics could be adequately represented and interpreted through qualitative inquiry. This first step strictly used inductive reasoning to examine the following system characteristics across the TCM: nature of hospital settings and network components, sensemaking of the surgical experience, connectivity among agents, feedback loops, and information flow. These are suggested dimensions for examining complexity in health care organizations in prior studies (Anderson, Crabtree, Steele, & McDaniel, 2005). In turn, such dimensions inform the conceptualization of the contour lines and building blocks for assembly of our three profiles and of TCM.

To further support the “dynamic” nature of our TCM, we apply thematic strings to the clusters of themes produced by cataloging open, selective, and axial coding. We specifically apply negative or positive arrows in a descriptive sense to understand the direction of the thematic interconnections across our TCM. This approach was strictly deductive and is used in complex network and system dynamics to understand how events are linked and change over time (Sturmberg et al., 2013). Similar approaches in qualitative inquiry, such as Event-Structure Analysis, are also used to examine directionality across events over time (Abbott, 1992, 1995).

Finally, we used theoretical saturation to ensure that we collected sufficient data as we described thematic concepts (Charmaz, 2006). This was determined by the study team through analyzing the recorded patient interviews up to the point at which no new information added further value to the study. Furthermore, to ensure consistency in data interpretation, we used data triangulation to validate our findings. All team members reviewed the coding process and discussed disagreements at joint meetings between the study team and clinical personnel involved in surgical care. We also formed an interdisciplinary team to foster both complementary and divergent understandings of complex phenomena at every step of the interpretation process. The coding process was organized with the use of the data analysis program NVivo (Bazeley & Jackson, 2013).

Results

The DTCS results help us to understand how patients perceive the workings of hospitals and other dimensions of the system, how their experiences with medical services are used to rationalize their current behaviors, how agents are connected in the process, how knowledge is acquired and informed by feedback loops associated with hospital services, and how the flow of information facilitates connections and educational coherence. For instance, patients reported understanding the diversity and dynamic network components of hospitals (initial complex system characteristics) and identified providers involved in the process of care (e.g., nurses and doctors). Patients also described the activities of these providers as “busy,” the environment as “fast paced,” and the whole organization performing like a “business.” This evidence informed the assembly of our TCM, and helped us understand how patients view themselves to be part of a complex system (see Table 1). We then examined these themes and their relationship to thematic clusters across our three profiles.
Table 1. Thematic Characteristics of Complex Systems Defined by Patients’ Narratives.

<table>
<thead>
<tr>
<th>Thematic Characteristics and Definitions</th>
<th>Patient Excerpts</th>
<th>Thematic Properties</th>
<th>Significance</th>
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<tbody>
<tr>
<td>Diversity and dynamic network components: A large number of elements interacting dynamically</td>
<td>“I understand the method of the hospital staff, nurses, doctors, and the chain of command. . . there is only so many nurses, I mean it is business.” “The hospital is fine it’s just it’s a big old hospital you kind of get intimidated by it.”</td>
<td>Busy, lack of scalability, perceived as a business, intimidation.</td>
<td>Health care delivery is perceived as a fast-paced, business model of operation. Patients are not aware of the systems behavior as a whole.</td>
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<td>Sensemaking and history, whereby the past shapes present behavior: The ongoing retrospective development of plausible explanation that patients use to rationalize their behavior and responses</td>
<td>“This is not my first, this isn’t even my second major surgery, this is my third, actually it’s my fourth surgery in my abdominal area . . . . So I’m pretty experienced for this type of surgery down there.”</td>
<td>Experienced, knows what to expect.</td>
<td>Establishes how patients may personalize and understand their treatment plan, and construes future behavior.</td>
</tr>
<tr>
<td>Connectivity: How patients in a system connect and relate to other agents that constitute the system</td>
<td>“My wife’s a nurse practitioner. She can take care of me. In fact she’s going to pull out the staples.” “She [my wife] gets upset for two reasons, because I smoke cigarettes and I smoke pot. Those things get her angry and she will go off now and then.”</td>
<td>Connectivity may include both positive and negative experiences.</td>
<td>Understanding patients’ support systems may require clinical probing of the quality of the relationship</td>
</tr>
<tr>
<td>Feedback loops: Patients as learners go through a cycle in which they acquire knowledge, assimilate, experiment, and then normalize the learning into their daily activities informed by feedback loops</td>
<td>“. . . during discharge and I was unaware of how that process worked, so I was calling the head nurse and she said, ‘I don’t discharge.’ I go on, ‘Who is it then?’ She says they didn’t know. I mean sure they are busy . . . I am not the only guy going home that day, I understand, but that seemed a little cumbersome.”</td>
<td>Frustration with unknown and uncertain need to understand</td>
<td>Patients may overcome their negative expectations once they understand how the system works</td>
</tr>
<tr>
<td>Information flow: The flow of information that facilitates connections across care settings and phases</td>
<td>“After the doctor told me what type of surgery I was going to have, I spent some time reading and looking at YouTube videos and that sort of thing and you know everything kind of fell in to line. But all these cases are unique, everybody’s surgery is not—none of this is routine—so your response recovery is not going to be routine.” “I got on my chart, where you can see and know everything about yourself from the surgery and blood work and all that kind of stuff, that’s kind of neat.”</td>
<td>Active learning, understanding of personalized self-care, communication barriers between patient and care team</td>
<td>Patients who have little or no former medical experiences may benefit from using online tools as venues of information to inform their surgery.</td>
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Profile 1: Inpatient/Hospital Settings

Patients’ prior experiences with hospitals and surgical operations substantially influenced their attitudes, expectations, and the learning process about their surgery as a whole. For instance, patients with previous hospitalizations reported feeling prepared to deal with the surgical procedure and associated pain and to navigate the expectations of care providers. In some cases, patients with multiple prior surgical experiences perceived obtaining assistance from care providers as superfluous and felt they knew exactly how to perform self-care behaviors. In contrast, among those with little or no formal experience with doctors and hospital settings, confusion and anxiety were a dominant theme. In some instances, these patients struggled to understand the process of surgical care. For these patients, however, using Internet tools was a useful source of clarifying information about their surgery and for self-education. Many of these patients also relied on the medical experiences of friends and family to understand their own surgical care experience.

The majority of concerns associated with hospital settings revolved around patient dissatisfaction with hospital accommodations, busy staff, and lack of support from staff on the weekend. Patients also indicated difficulty sleeping due to background noise and poor quality of hospital beds. However, we found that patient dissatisfaction was due, in large part to the incongruence between hospital and home experiences. For instance, patient dissatisfaction with hospital accommodations and services was due to a preference for home environments over hospital settings. For excerpts of Profile 1, see Table 2.
The quality of information received was a relevant factor for patient discharge. Most patients described the discharge process as informative and thorough and reported an overall positive educational experience during the discharge process. A few patients, however, commented that the discharge educational process excluded their home care providers, family, or partners, and wished that the training and involvement of family members were part of the preparation for discharge. Finally, a few patients wished they had received more information about their medications, not because adherence was a complicated matter, but because they had no experience of a given medication and wanted to know more about how its effects would affect their treatment.

We also found that by the time patients had gone through pre- and postsurgery phases, most of them felt ready and eager to leave the hospital and return home. Patients found the process cumbersome, and some reported concerns about the long wait during the discharge process, which inconvenienced family members picking them up. A common reason for patients pushing for discharge stemmed from pressures to return to their loved ones and their more comfortable home environment. For most patients, the source of their frustrations and disappointments with the discharge revolved around staff being too busy, last-minute administrative work, and
failure of the staff to keep to the planned discharge timing. Finally, similar to the findings of the previous profiles, some patients compared their current discharge experiences with previous ones, suggesting the importance of patients’ prior experiences in relation to the discharge process. For excerpts of Profile 2, see Table 3.

**Profile 3: Home Environments**

Home environments were instrumental for supporting physical activity and surgical rehabilitation (see Table 4). The variation of home spaces and layouts supported patients in different ways. For some patients, the home environment was positive and therapeutic. Some homes provided enough space to enable patients to gradually carry out physical activities and regain physical abilities. For instance, some patients reported performing their physical activity regimens inside their large homes. In contrast, patients who did not report any benefits from their home environment for physical activity reported utilizing outside locations such as parks or Young Men’s Christian Association (YMCA) facilities. Particularly notable about this theme is how winter weather conditions affected patients differently; winter was more challenging for those patients who depended on outside locations for their physical activity.

When asked to discuss the role of their partners, families, or other home support systems, the quality of relationships at home played a significant role in the recovery process. Specifically, the quality of relationships emerged as taking on three different forms. In the first, superior personalized support was provided to patients by their partner in the form of trained medical assistance. For instance, in some cases, the caregiver was able to remove bandages or even remove stitches. In the second form, some patients reported receiving adequate support from their partners in day-to-day home activities such as cooking and laundry. In the third, for a few patients, home support was not as relevant given that they felt autonomous enough not to need assistance. Finally, in some instances, conflict was experienced between partners related to behaviors such as smoking.

Despite the different ways in which home environments and support systems helped patients recover, most patients exhibited a strong sense of commitment to the recovery process. For instance, patients highlighted the importance of healthy eating, giving up alcohol and certain foods, sleeping well, having constant contact with...
**Table 4. Profile 3 of the TCM model Depicting Themes Associated With Home Environments.**

| Home environment can be therapeutic | I have been very compliant about what I should do and what I shouldn’t, in fact today, I did a lot of walking, we have an indoor in-ground pool and I walked, it’s a 25,000 gallon pool, and it’s nice I don’t want to walk outside because of snow and slippery, so walking around the pool a ton of times gives you good exercise and it’s nice and warm and what have you. So I have been compliant as far as what you should do and I think that helps also. My house is a ranch, I mean I have a full basement but I don’t need to go down there so I pretty much walk around the whole interior of the house several times a day, checking out the window and of course we have all the snow here, so it is kind of interesting. Other than that I think that I’m doing pretty well. |
| Home environment may impose limitations for postsurgical recovery | We have snow blowing just north of us and can get a couple of feet. . . It’s a little unfortunate, I have to put a bunch of gear on and go walking around and I just don’t like doing this . . . walking around town is very easy and I’d like to be able to do that, but the weather is getting pretty foul, so it’s a little difficult to get outside and walk . . . I’m sure I could put a whole bunch of clothes on and go outside and walk around [in the snow]. I don’t want fall down, you know I think falling down would be a bad thing . . . so I’m walking in my house. I am walking around the treadmill [at the local YMCA]. I am up to 2 miles and I do a 2% incline I walk between two and a half and 3 miles an hour so I get to burn some calories. Then use other machines, two for legs, four for arms and two for leg crunches so I am getting back, not where I used to be but I am comfortable. I want to walk but the weather [snow] you know . . . when the weather gets nice, I can get out into the parks and start walking and get some exercise that way, but have not been able to do any exercise in any other way . . . I could probably do other things as far as exercising, but right now I really want to start walking. |
| Informal caregivers can make a positive contribution to the recovery process | My wife is a nurse practitioner; she can take care of me. In fact she’s going to pull out the staples. I don’t know what I would have done without her. I mean she is my support, and I’m hers, but I mean in this particular case she is my support; she has helped every way, shape, and manner, and I am very blessed to have her. Yes, my wife is helping me. She’s cooking my meals for me and she’s doing all that so that’s good for me. My wife is making me homemade meals which are pretty good and so far everything is going good . . . every night my wife and I empty the drain out of whatever has come out of my stomach and measure it, and then in the morning we flush the tubes so that it’s all clear so that the things are working properly. My wife of course has helped me tremendously . . . but she gets upset for the reasons that I smoke cigarettes and I smoke pot. So those things get her angry and she will go off on me now. I am who I am, I think we have been through that. “Not so much [help from family members]; just a little bit, she [the wife] and my daughter, but you know I am pretty much independent; I am pretty much doing everything.” To be honest, right after the hospital I do everything on my own because even this episode I have had surgeries before, and I found that you need to get up and do things; you can’t just sit on the couch because that is not a good thing. Because if you let other people do things for you, you will never get back into the proper mode. I mean, maybe once in a while my wife would give me something to drink or something like that, but if I wanted something I’d get up and get it myself. |
| Patient recognize the need for behavioral change after major surgery | Patient recognize the need for behavioral change after major surgery. I have been very compliant about what I should do and what I shouldn’t, in fact today, I did a lot of walking, we have an indoor in-ground pool and I walked, it’s a 25,000 gallon pool, and it’s nice I don’t want to walk outside because of snow and slippery, so walking around the pool a ton of times gives you good exercise and it’s nice and warm and what have you. So I have been compliant as far as what you should do and I think that helps also. My house is a ranch, I mean I have a full basement but I don’t need to go down there so I pretty much walk around the whole interior of the house several times a day, checking out the window and of course we have all the snow here, so it is kind of interesting. Other than that I think that I’m doing pretty well. |

(continued)
Table 4. (continued)

| Self-motivation and self-care | Once again, the biggest thing when you are at home is to make sure you stay as active as possible. I’m not saying you have to go out and run a marathon or even go back to work, but you need to be up and... you can’t just sit on the couch and become a vegetable; you’ve got to get up and walk, moving around actually helps. It doesn’t feel well getting up at first because of the pain but then again the pain meds help that so once you’re up and moving around you’ll find that moving around you actually feel better.

You hear about people who have problems because they don’t take care of themselves... even your own body chemicals can cause infections and things like that, that is my biggest fear I think, making sure everything stays clean and proper and no infections. I don’t want anything to go backwards on me, I’m taking my footsteps ahead, I’m getting out of this and past all of this... I don’t want to have to go back and start over again. I guess that was one of my biggest fears and as everything seems to be getting so much better and is making me feel more at ease, a lot more at ease now.

That’s always an issue [being far away] that I dealt with prior to choosing this [name of hospital] for surgery and treatments. As another patient stated, “...I was ready to go home and be able to relax even more because hospitals are not that comfortable to heal in.” See Figure 1, Profile 2, Time I.

A second connection linked to the hospital and home settings was found among those patients with prior surgical or formal medical experiences. This connection reveals agreement among patients about their perceived readiness for discharge. For instance, when asked about the quality of communication and coordination of care, most of these patients felt experienced enough to know what to do. One patient stated, “... they all [i.e., the care team] told me the same thing... they didn’t have to spend a lot of time with me because I knew exactly what to do.”

In contrast, patients with no prior formal medical experiences perceived the quality of information and the discharge process as essential and well coordinated, finding their discharge instructions helpful and useful. As a patient with no prior formal medical experiences stated, “[I received] pretty much everything I needed [to be discharged], I went through the discharge plans with the nurse and they were fairly thorough.” These themes were also linked to patients yearning to learn more about their surgery and treatments. As another patient stated, “... after I was told what type of surgery I was going to have,

| Coordination of postdischarge follow-up care | Being this far away [from the hospital] and then trying to coordinate between the two doctors has been difficult, not necessarily for me but for them because they are the ones that have done it all. I didn’t have to do it, they did it themselves, they didn’t leave it up to me to have to do it, so their schedulers both got together and figured it out... I am going to have to make two separate trips... the care team have been very accommodating.

That’s always an issue [being far away] that I dealt with prior to choosing this [name of hospital] for my cardiac ablation and for this surgery. You know that’s just the chance you take when you are farther away, but my perspective being at a university center with the team approach was more important than being local with a single colorectal surgeon.

Note. TCM = transition of care model.

care providers, and carrying out physical activities. One of the biggest challenges for some patients with regard to diet was to drink enough fluids to keep hydrated, which they knew to be important. Finally, most patients recognized the importance of staying active, preventing infection, and making gradual progress. Accessing their health records online (Mychart) was a tool used to inform their treatment and progress. For some patients, the fear of recurrence was enough of a motivator to take the necessary steps to improve their condition. For excerpts of Profile 3, see Table 4.

Cascades and Thematic Interconnections

Three key interconnections across clustered themes and profiles were discovered. The first links home and hospital settings and demonstrates how patient dissatisfaction and discharge experience were in large part attributed to the contrasts between hospital and home experiences; for some, going home was perceived as therapeutic, with patients referencing better conditions for sleep, physical activity, and recovery. One patient said, for example, “When discharged, I was ready to get the hell out.” Other themes highlighted the discharge process as “chaotic,” “cumbersome,” and “taking forever.” These patients also reported dissatisfaction with their hospital stay after leaving the hospital. For instance, a patient stated that “... everyone is busy and there isn’t excess staff, I am sure, but there should be a more orderly process [when discharged].” These reasons were found to be linked to differences in home and hospital settings, as the patient later states, “I wanted to be in my own bed, you know, wanting to kind of be surrounded in my own familiar surroundings, and you don’t sleep much in the hospital. I was looking forward to a good night’s sleep.” Similarly, another patient stated, “I was ready to go home and be able to relax even more because hospitals are not that comfortable to heal in.” See Figure 1, Profile 2, Time I.

A second connection linked to the hospital and home settings was found among those patients with prior surgical or formal medical experiences. This connection reveals agreement among patients about their perceived readiness for discharge. For instance, when asked about the quality of communication and coordination of care, most of these patients felt experienced enough to know what to do. One patient stated, “... they all [i.e., the care team] told me the same thing... they didn’t have to spend a lot of time with me because I knew exactly what to do.”

In contrast, patients with no prior formal medical experiences perceived the quality of information and the discharge process as essential and well coordinated, finding their discharge instructions helpful and useful. As a patient with no prior formal medical experiences stated, “[I received] pretty much everything I needed [to be discharged], I went through the discharge plans with the nurse and they were fairly thorough.” These themes were also linked to patients yearning to learn more about their surgery and treatments. As another patient stated, “... after I was told what type of surgery I was going to have,
I spent some time reading and looking at YouTube videos and that sort of thing” (see Figure 1, Profile 1).

The third interconnection highlights several inputs and outputs associated with patient experiences at discharge using the graphing technique in a descriptive sense. First, as indicated in earlier excerpts, we found that patients who reported receiving clear and consistent messages during their surgical care reported feeling prepared and satisfied with the discharge process in turn. In contrast, other patients attributed their frustrations during discharge to the busy nature of the surgical care staff. A patient stated that “People [staff] are busy in [the] hospital . . . if there is any one thing that they can do [better] this time was to make the discharge happen a little faster.” Similarly, another patient states, “We were sitting in the room for 3 hours waiting for [discharge] to happen, so you are looking at 8 hours later from the time that the attending physician says, ‘Hey, you are good to go home,’ and by the time you actually walked out the door it was cumbersome.”

Further analysis revealed a link between patient frustrations at discharge and previous communication breakdowns, specifically the lack of staff during the weekend. For instance, a patient frustrated with the busy nature of the discharge process also highlighted experiencing prior communication difficulties during his hospital recovery over the weekend: “I don’t think the staff was as good on the weekend as it was during the week . . . I waited 45 minutes for somebody to come.” Taken together, these links describe inputs and outputs that may either support or hinder patient experiences during discharge. (See Figure 1, Profile 2, Time III). The overall body of evidence in our TCM presents a comprehensive picture of the interconnected experiences that patients undergo before and after surgery.

**Discussion**

Current care delivery practices are in need of a paradigm shift as the number of treatable conditions grows, with treatment modalities becoming more complex and relying more heavily on patients’ ability to provide self-care and coordinate their appointments (Plsek & Greenhalgh, 2001;
Bloom, 2002). The social-complexity network approach allowed this research to identify many important links for patients undergoing a colorectal resection. Yet the strength of this study is its multidimensional assessment of patient experiences across different contexts and points of care. Findings from patient interviews reveal five qualitative features involved in assimilating a complex system which, in turn, helped assemble the dynamic experiences of patients across different stages of care and care settings. Subsequently, within each of the three profiles (hospital, discharge, and home environments), there are clusters of shared experiences about patient satisfaction, anxieties, technology usage, discharge readiness, personal home environments, and surgical adaptation, to name a few. Yet this research goes deeper into the meanings of patients to identify cascades and connections within the networks of their experiences.

To our knowledge, this study is the first to map networks of patient experiences across the surgical care pathway, providing fresh insight into interventions that can improve quality of surgical care and prevent hospital readmissions. Within this body of evidence, patients’ prior medical experiences (whether formal or informal) and their home environments are key experiences that shaped the course of their recovery. These findings can inform patient-centered practices and highlight, for example, why some patients may decline to ask providers questions about their problems, or fail to discuss the conditions present in their homes. For instance, a clear distinction emerged between those patients with prior medical experiences and those with little or no formal experiences. Those patients who had previous hospitalizations were more accepting of the recovery process and any pain associated with the surgical procedure, and also reported a better understanding of the expectations associated with the surgery. In the health care literature, the concept of sensemaking has been used to describe how individuals attempt to understand a new situation (Davidson, 2010; Weick, Sutcliffe, & Obstfeld, 2005). Therefore, allocating sufficient time to discuss patient expectations and prior experiences as a part of preoperative training and risk assessment is likely to help patients adapt to changes in their health status and care environment (Waitzkin & Britt, 1989, 1993).

The overall evidence of this research highlights many important patient-defined outcomes in surgical care. Therefore, we argue that a linear focus on health care efficiency and revenue may also limit the amount of time that providers can spend with their patients, limiting opportunities for successful patient–doctor communication and compromising patients’ ability to develop trust in their providers—one of the main reasons for patient dissatisfaction with care and poor outcomes. Our findings emphasize the importance of recognizing the adaptive character of patients and health care delivery processes. For instance, considering informal caregivers as a part of the treatment team and offering them the same training as the patient receives allows caregivers to provide situational monitoring and to serve as backup to patients when they are unable to perform self-care tasks (Weaver et al., 2013).

Another strength of our study is the use of innovative methodologies to examine complex systems. The integral utilization of the DTCS, SACS Toolkit, grounded theory, and complex modeling graphing techniques has the potential to promote new directions in clinical practice although further empirical testing is still required. While there is no accepted standardization of complexity in qualitative inquiry, this research is a step in that direction. Utilizing these tools and techniques may suggest new quantitative and qualitative strategies compatible with the complex character of individual medical experiences. Therefore, the current study also represents a new direction for research, practice, and analysis more than it reflects a finished product: Our hybrid approach provided a more comprehensive view of the challenges and opportunities patients face and may serve as an important foundation for patient-centered practices and guidelines aimed at improving transitions of care among patients undergoing surgery.

**Limitations and Conclusion**

The attempt to understand transitions of care as a complex system from a patient’s point of view has limitations. The collection of patient interviews used for this analysis did not reflect the views of health care providers or support systems. Future research may improve upon this limitation by including qualitative interviews with health care providers and caregivers. Because all data collection was performed at a single hospital, findings may not be generalizable to other hospital settings but may be reasonable and transferable in multiple contexts that include home environments. In addition, a larger scale quantitative survey may be needed to assess the relative importance of processes and system characteristics reported by individual patients and providers.

Health care delivery has increasingly functioned as a complex system because health care consists of a wide range of services with nonlinear interdependencies and autonomous agents that can adapt and learn. Complex systems approaches, such as agent-based modeling, network analysis, and engineering control methods, have been effective at describing the dynamical activity of large-scale systems (Begun et al., 2003), which ultimately allow us to understand emergent interdependencies in health care delivery, including management (Plsek & Greenhalgh, 2001), nursing (Clancy & Delaney, 2005), and continuity of care (Sturmberg, 2003; Wolstenholme, Monk, McKeirvie, & Arnold, 2007). These methods are
widely used, yet they often fail to focus on an important element of the care pathway: the patient experiences embedded in the contexts in which they live and recover.

This study lays out a rationale for understanding complexity across transitions of care as described by patients’ narratives. The level of complexity is conceptualized and measured in terms of the interrelatedness of themes associated with patient experiences and stories across contexts of surgical care (inpatient/hospital settings, discharge, and home environments). This process of functional deconstruction is possible when guided by a conceptual model linking the health care system’s organizational components, patient preferences, and the interactions between them. Future research should expand our exploratory framework to conceptualize and identify change across transitions of care and use the set of observational tools (SACS Toolkit, grounded theory, and graphic presentation of thematic interconnections) to analyze patients’ settings, such as their homes and communities, in a way that recognizes and accommodates the elements of complexity in these systems. Most importantly, treating care pathways as a dynamic system informed by the voices of patients may serve as a foundation for patient-centered practices and guidelines aimed at improving transitions of surgical care.

Authors’ Note
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References
Agar, M. (2004). We have met the other and we’re all nonlinear: Ethnography as a nonlinear dynamic system. *Complexity, 10*, 16–24. doi:10.1002/cplx.20054


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