

Routines That Ease the Pain: The Information World of a Dialysis Clinic

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ABSTRACT

Patients with kidney failure who receive hemodialysis must spend 12 hours per week in a clinic setting to stay alive. We conducted an ethnographic study in a dialysis clinic in a Midwestern state that included 51 hours of observation and in-depth interviews with 9 clinic patients. Using Chatman's "Theory of Life in the Round", we examined how staff and patients in the dialysis clinic exchanged information about the disease. Information exchanged in this world was oriented towards making illness and treatment tolerable. Through immersion, staff and patients demonstrated how to live on dialysis, often with the aid of escapism and gentle banter. They also developed a taken-for-granted worldview marked by psychological acceptance and a local, everyday focus. This worldview was supported by the establishment and repetition of routines that reinforced the taken-for-granted quality of dialysis. Informational routines in the clinic also helped to convey this worldview, while systematically informing patients about how to live on dialysis. Patients generally stepped outside of this information world only if they received a kidney transplant, experienced a new health crisis, or came to distrust their health care providers. Implications for information behavior theory and clinic-based information services are discussed.

Keywords

Information behavior, ethnography, theory of life in the round, health care, end-stage renal disease

BACKGROUND AND PURPOSE

People with end-stage renal disease (ESRD) require dialysis or transplantation in order to survive. Ninety-three percent of ESRD patients undergoing dialysis receive treatment in a clinic setting ("hemodialysis") (U.S. Renal Data System, 2009). This generally involves being connected to a dialysis machine for about four hours at a time, three times per week. Dialysis is accompanied by demanding dietary and fluid intake restrictions, fatigue, and other symptoms that

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may limit one's activities (Clarkson & Robinson, 2010). Dialysis may place a heavy burden on patients and decrease their quality of life (Fukuhara et al., 2003), even though it helps them stay alive.

ESRD patients have significant needs for information on topics such as diet, treatment options, symptom management, and insurance (Ormandy, 2008). Information-based interventions have been found to aid in treatment decision making and health management among ESRD patients (Mason, Khunti, Stone, Farooqi, & Carr, 2008). Health care providers are important sources of information for ESRD patients (Orsino, Cameron, Seidl, Mendelsohn, & Stewart, 2003). This is likely reinforced by the ESRD patients' unusually frequent contact with health care providers and other patients. Despite the unique characteristics of dialysis clinics, their particular role in informing ESRD patients about their illness has not been systematically examined. To address this gap, we investigated the information world of a hemodialysis clinic and the related processes by which patients acquired disease-related information in this setting.

Theoretical Framework

In its focus on information behavior in an institutional environment, Chatman's (1999) "Theory of Life in the Round" was germane to this study and will be used as an analytical lens through which to examine study data. This theory asserts that certain groups of people live in "small worlds" in which people share a common worldview. Developed out of research in a women's prison, the theory suggests that people acquire information for the purpose of assimilating to their environments. Small worlds are characterized by a "life in the round," routine activities in which daily life is taken for granted, local experiences are central, and information seeking is largely unnecessary. People who dwell in small worlds together set limits on behavior through social norms that define appropriate information behavior. People will not look for information outside of their worlds unless their need for information is critical and their worlds are no longer working.

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METHODS

This research took an ethnographic approach, including observations and interviews with patients in an urban dialysis clinic in a Midwestern state. We conducted 51 hours of observation, in sessions of approximately two hours, during which time field notes were recorded. In-depth, semi-structured interviews were also conducted with nine clinic patients regarding their information behavior and clinic experiences. Patients were selected to represent variation in observed in-clinic behavior. Interviews lasted approximately two hours and were transcribed. Categorization and coding of data were conducted using NVivo software. The study was approved by the Institutional Review Board of the University of Michigan.

FINDINGS

Demographics of Interview Participants

The average age of interview participants was 65. Five were male and four female. Four were Caucasian, four were African American, and one was Asian. Four had completed high school, four had education beyond high school, and one had not completed high school.

The Setting

The dialysis clinic had two main regions for patients: the waiting room and the dialyzing room, set apart from one another by a locked door. The waiting room had chairs for up to 10 people. Small tables held popular magazines or brochures. One wall displayed a bulletin board with kidney disease-related posters and flyers. The room also contained one television. The dialyzing room was large, with open space and counters at the center. A total of 16 patient chairs and dialysis machines were widely spaced along two opposite walls. Each reclining chair was equipped with two small armrest tables and faced a personal television.

The dialysis routine began with most patients arriving and sitting in the waiting room, where they often interacted as they awaited their summons into the dialyzing room. In the dialyzing room, patients proceeded to a large scale, where they were weighed prior to treatment. After this, patients moved to their reclining chair, where a technician hooked them up to the dialysis machine with large needles and tubing. As patients dialyzed, staff moved around them. At completion of dialysis, patients were unhooked from the machines and weighed themselves, and then left the clinic or sat in the waiting room to wait for transportation.

The Information World

Most dialysis patients longed to be freed of the discomforts and demands of treatment. Many complained of feeling cold, tired, stiff, and/or thirsty while dialyzing. Some also felt nauseous or experienced painful cramping. Between treatments, some suffered fatigue, disrupted sleep, or loss of appetite. They also complained about lifestyle restrictions, as this patient said: "...you no longer can do what you used to do.... I don't like to come in here. I got to go in there three days a week ... that's kind of depressing...."

Yet most patients remained committed to their treatment because they recognized that without dialysis, they would die rapidly, as this patient said: "...you deal with it, because if you don't deal with it, you're not going to live too long." Given this, whether awaiting a transplant or not, the fundamental issue facing patients was how to make dialysis tolerable. Thus, while not as socially constrained as the prisoners studied by Chatman, dialysis patients also used information to help them survive their situations. Hence, the information sought, shared, and used in the clinic was oriented towards the purpose of finding a way to go on.

Learning to Live on Dialysis

How did the information world of dialysis clinics help people learn to tolerate treatment? Through immersion in an information-rich environment and the repetition of treatment routines, patients gradually learned to deal with common problems such as discomfort/pain, boredom, dependency, and lifestyle restrictions. The environment also provided examples of visibly ill people and deaths of fellow patients that reinforced the necessity of treatment.

In keeping with Chatman's theory, the information world of the dialysis clinic was comprised of numerous informing elements that together gave patients most of the information they needed. These elements included caregivers with educational roles; informing events; the appearance, actions, and stories of other patients; the behavior of machines and instruments; and laboratory results. Patients also learned to read their physical sensations and experimented with new routines and remedies with the aid of others.

With regard to the problem of physical discomfort and symptoms, patients learned through trial and imitation to bring comforting items with them to the clinic, such as blankets, headphones, reading material, and food. Through experience, patients also learned how to manage symptoms such as cramping, as this patient described: "*I know now what the feeling is before you're going to cramp. So, I know that, OK, I either want to change the goal or I want them to give me some saline.*" Staff such as technicians and nurses also offered advice and remedies to reduce symptoms, such as painkillers or antacids. Some even playfully arm-wrestled with patients to prevent their blood pressure from dropping. Over time, each of these lessons helped patients to build a treatment routine, as this patient explained: "*...as time go on, you learn more every time ... you ... get all the answers [from] the experience.*"

For problems of boredom, patients came to rely on forms of escapism common in the environment. Many patients slept to pass the time, as this patient explained: "*...if you can manage to sleep two hours ... you only got two hours to deal with it and wait ... everybody in here sleeps.*" Watching television was also common for this reason. Indeed, dialysis clinic staff actively coached patients to engage in such activities to make treatment tolerable, as this staff member emphasized to a resistant patient, "*You can watch TV while you're here, listen to music....*"

Dependency on clinic staff, as well as limited mobility during dialysis, were also psychically challenging for some patients. Here, staff and other patients played a particularly vital informing role by demonstrating the power of humor to lighten the experience. Joking and gentle banter were ubiquitous in this clinic and often revolved around making light of the situation and its indignities, such as when staff joked about enjoying giving patients needles or when this patient who had more than three hours left of dialysis joked: *"I'll just run off and be back soon."* Witnessing, and being drawn into, such humor can be thought of as a series of informing events about humanizing a difficult situation.

Problems with a restricted lifestyle, particularly around diet, were also progressively addressed through clinic-based informing. Staff informed patients about food and fluid restrictions in various ways, including one-on-one consultations, ad-hoc feedback, and response to questions. Additionally, often in the waiting room, patients shared personal experiences with such restrictions. For example, this patient said that he asks others: *"what their intake is on alcohol or do they like seafood."* Such feedback helped patients to learn about how to live with such restrictions.

As would be envisaged by Chatman's theory, an interesting aspect of this type of information is that it was at least partly produced within the world of the dialysis clinic, and thus was tailored to the needs of people in that world.

Worldview Formation

In accordance with Chatman's theory, informing directed towards making treatment tolerable helped patients to develop a common kidney disease-related worldview that matched the demands of the situation. This worldview was one of acceptance and a determination to make the best of things, as this participant said: *"You just accept what it is. And you move on. It don't stop me from doing anything else. The days when I'm tired, fatigued, I go back and go to sleep. That's about all you can do."*

This worldview was thus oriented towards the everyday, local experience of dialysis. It also helped to create the boundaries of an experience that became increasingly routine and taken for granted. Yet this worldview also supported the value of escape. Like Chatman's prisoners awaiting probation, patients sought kidney transplantation as a "way out," they spoke frequently about transplant prospects, and transplant-related information seeking became subtly obligatory, as this patient complained: *"They talk about it but ... right now I'm not into nobody's opinions about what they think I ought to do...."*

The Role of Routines

The routinized character of clinic life supported the worldview of dialysis patients. As outlined above, dialysis has a rigid schedule and involves steps repeated during every visit. Patients may also develop their own treatment routines in order to learn to better tolerate dialysis. Chatman's theory labels such a routinized style of living as a "life in the round." Routines provide predictability, giving

one's world a taken-for-granted character and providing personal security. In this way, clinic routines may have soothed the pain of a life limited by renal failure.

Chatman emphasizes that a life in the round reduces the need to seek information. While this was the general case in the dialysis clinic, the environment also possessed a type of routine not explicitly envisaged in Chatman's model: information routines that provided patients with a predictable route to information. A routine can be defined as a "coordinated, repetitive set of activities" (Miner, Ciuchta, & Gong, 2008) that may be undertaken at a group level. Information routines were often embedded in dialysis procedures themselves. Dialysis treatments began with a technician taking the patient's vital signs, while asking standard questions about how he or she was feeling. Any problems or requests were then recorded and relayed to others for follow-up. Additionally, staff gave patients regular updates on their treatment progress, particularly the time remaining in their treatment. Patients were also given several information sessions as a part of their intake. Intermittent staff rounds and informal visits provided the opportunity to deal with emergent issues, and monthly lab reports were discussed at length.

Between patients, interactive, informative routines were also evident. Daily greetings, for example, provided an opportunity to monitor the health status of other patients. With frequent deaths among patients, such monitoring was a particularly poignant part of the daily routine, as this patient explained: *"You see these people every day that you come. And it's good to see them, but the hardest part ... [is that] you don't know where life's gonna bring you tomorrow...."* Waiting room small talk also allowed patients to informally learn about one another's experiences. This talk often focused on common subjects, such as: *"...how long they've been on, and what their diet is...."*

Notably, many patients came to trust that these routines and the clinic staff would give them whatever information they needed. Thus, they came to take the availability of information for granted; moreover, the intensity of their own needs for information reduced as they progressively learned how to live on dialysis. As this patient explained: *"I put myself—I put my health in their hands. I really do."* Routine information exchange also meant that patients rarely viewed themselves as having "sought information"; they simply relied upon information that was "already there" in the clinic, as this patient described: *"If there's any new information, I'm glad for that.... I try to listen and hope I'll pick up something."*

Stepping Outside the Information World

Chatman's theory predicts that, as long as their worlds continue to function well, people who live a life in the round will rarely step outside of their worlds to look for information due to the group's social norms. These norms are given force by the fact that people in small communities have little privacy and are thus subjected to public scrutiny.

In contrast to Chatman's theory, the dialysis clinic exerted incomplete scrutiny, and thus imperfect social control, on its participants. Although patients felt constrained by dialysis, they lived lives outside of the clinic. Hence, the clinic might be thought of as a world with porous, rather than solid, boundaries. Additionally, although activities in the clinic took place in the presence of others, people were conscious of the need for privacy. Thus, staff and patients often gave patients respectful distance, and the "awayness" (Goffman, 1963) provided by sleep, reverie, or television was tolerated. In the close quarters of the clinic, unacquainted patients also accorded one another "civil inattention" (Goffman, 1963). Such behaviors meant that patients did not generally experience powerful public scrutiny of their behavior. But despite the absence of strong social control, patients generally stayed within the information routines of the dialysis clinic. They explained this from a positive perspective, grounded in the abundance of useful information and interpersonal trust.

DISCUSSION AND CONCLUSION

There is increasing research interest in information production, sharing, and use in communities (Talja, Tuominen, & Savolainen, 2005). While an emergent field, Chatman's often-overlooked Theory of Life in the Round is an important attempt to conceptualize the features of everyday life communities that matter for information behavior. The present study provided expanded empirical support for Chatman's theory, further illustrating how a group may develop local information that is shared and used within an immersive information world. However, this research also points to a limitation in this theory: the fact that it has its empirical basis in an atypical social group joined by enforced captivity. As this research shows, groups may be held together by less compulsory forces, yet nonetheless shape a collective information world in powerful ways. Thus, there is a need to develop conceptual frameworks of community-level information behavior that accommodate different degrees of community boundedness.

This research introduces the concept of a group's "information routines." As an organizational analogue to individual habits, routines carry information and facilitate learning (Miner et al., 2008). This research points to the potential utility of investigating everyday life information behavior in groups from the perspective of their routines, building on the analysis developed here. Such an approach may be especially fruitful since individual information behavior is often habitual (Harris & Dewdney, 1994), a property that may also extend to groups.

Finally, this research suggests that information services directed to dialysis patients should focus on close integration with the clinic's information environment. One option would be to provide patients with information technologies while dialyzing, thus providing a stimulating way to pass the time. Another possibility would be to provide peer-mentoring programs in dialysis clinics, such that patients have systematic access to trained peers with a

more cosmopolitan perspective. Peer mentors could also cultivate the position of what Chatman termed "lifers"—trustworthy people who provide information tailored to the unique challenges of patients' everyday lives.

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