A. Description of proposed research

Personal health information is increasingly sought and shared on the Internet. Some people with lifelong chronic conditions turn to online support groups focused on their condition for social support, which often includes the exchange of personal health information. This trend is likely to continue, as the prevalence of chronic disease in the United States is rising. However, we do not understand how people search for and share health information in online support groups. This proposal outlines a grounded theory dissertation that will address social support, information seeking, and personal health information disclosure on online support groups for chronic kidney disease.

Significance of proposed research

On June 23rd, 2011, a 24-year-old woman from Texas logged in to an online support group (OSG) for kidney patients and their caregivers. She began a new discussion: "I'm scared," she typed. The post that follows is not long, but it is detailed: she gives readers a quick recap of her diagnosis and current state (on dialysis, waiting for a transplant); she then lists some of her fears about post-transplant life. She's worried about imposing on potential donors, concerned about having a scar on her abdomen, and says she is terrified that she will forget to take her medications. She expresses fear that she is complaining too much, but then qualifies it by explaining that the forum feels like a judgment-free zone, a place where she can feel free to talk about her fears. She then asks for advice to overcome her fears. This young woman received nine thoughtful replies throughout the course of the day, including comments from people discussing their personal experiences post-transplant, links to articles about life after transplantation, and contact information to continue the discussion via email. The last commenter thanked the original poster for starting the thread, explained that she

had the same emotions, and was grateful that participating on the site provided her with support

that she couldn't get elsewhere.

On the surface, this post is a request for social support and information about living with a

kidney transplant; the young woman also discloses a fair amount of her own personal health

information. In this short post, one can see that the concepts of information seeking, disclosure, and

social support are inherently linked processes. To this researcher's knowledge, the relation of these

concepts is heretofore unexplored in the literature. Additionally, we do not understand basic things

about these concepts individually.

For example, although several theories of information behavior touch on information

transfer and information sharing, these theories mostly focus on information seeking and not on

information use (e.g. Wilson, 1999). We do know that patients have specific information needs that

generally arise from an uncertainty or gap, discussed in several theories focusing on information

behavior (e.g. Belkin, 1980; Case, 2012; Dervin, 1998; Kuhlthau, 1993; Savolainen, 2006; Wilson,

1997). For people with chronic kidney disease (CKD), several common information needs have

been identified, including but not limited to questions about symptoms, disease progression, the

impact of the disease on one's daily life, the meaning of test results, the influence of the disease on

one's financial future and career/work opportunities, and how to cope with the disease and its

symptoms (e.g. Groome, Hutchinson, & Tousignant, 1994; Harwood, Locking-Cusolito, Spittal,

Wilson, & White, 2005; Iles-Smith, 2005; Klang, Björvell, & Clyne, 1999; Lewis, Stabler, & Welch,

2010; Martin, Stone, Scott, & Brashers, 2010; Ormandy, 2008; Orsino, Cameron, Seidl, Mendelssohn,

& Stewart, 2003; Veinot, Meadowbrooke, Newman, Zheng, & Perry, 2010). These needs can be met

by multiple information channels. The most common channels consulted by patients are healthcare

providers, other patients, and the Internet (Fox, 2011a). In general, patients prefer to get

information from their healthcare providers (e.g. Fox, 2011a; Gollop, 1997; Lenz, 1984). However,

in practice they are more likely to go online to seek health information before talking with their

provider (Hesse, 2005). Although people prefer channels that exhibit social presence (J. D. Johnson & Case, 2012), it can be expensive and time-consuming to visit the doctor.

The context of the information need also plays an important role: patients are likely to ask healthcare providers about technical issues, such as prescription interactions and symptoms; they turn to other, more personal channels when they have more personal or experiential information needs (Fox, 2011b). People who are searching for experiential information online are not just looking for health information, but are also seeking social support from patients with similar diagnoses in order to make sense of their condition, learn about the psychosocial effects of their disease, and understand the impact of treatment options on their quality of life in order to aid decision-making (e.g. Chuang & Yang, 2010; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Ferguson & Kelly, 1999). Participating in OSGs makes patients feel more informed about their disease and enhances their sense of well-being, according to a survey of patients with life-threatening, unexplained, or chronic disabling conditions (van Uden-Kraan, Drossaert, Taal, Seydel, & Van De Laar, 2009). Obtaining support from other, similar patients is much easier on the Internet; therefore, this trend is also likely to grow. However, there is little empirical work on kidney patients' employment of online social support groups, and the work that does exist is intervention-focused. How people share experiential information via disclosure is one type of information use that would be welcome in the information science literature, as would work that investigates the use of experiential information by patients. The rapid growth of individuals using the Internet to search for and share health information indicates that we need to develop a more thorough understanding of these processes. Healthcare providers and patients alike can benefit from theories that attempt to explore and describe these phenomena.

We also do not yet understand why people share personal health information in OSGs. Some researchers posit that online disclosure is motivated by a desire for emotional support (Eichhorn, 2008), while others maintain that it is because people feel safe to explore their identity online in a

way that they do not in face-to-face interactions (Attrill & Jalil, 2011). To date, there is scant work that discusses the content of online disclosure (Barak & Gluck-Ofri, 2007). Research specifically focused on online health information disclosure will help to increase our understanding of how the type of information being disclosed may influence online behavior. In addition, most of the research on health information disclosure focuses on face-to-face encounters of diagnosis disclosure, although there has been a call in the literature for work that examines subsequent disclosures and the process of health information disclosure as it unfolds over time (e.g. Checton & Greene, 2012). This study will create a middle-range theory that describes the process of online health information disclosure over time rather than just focusing on the point of diagnosis.

Furthermore, this work will add to the extremely small body of literature focused on CKD patients and their use of OSGs (Godbold, 2010). Since the prevalence of CKD in the United States is rising – with some researchers even calling it an epidemic (Coresh et al., 2007; Coresh, Stevens, & Levey, 2008) – and an understanding of how patients with this illness behave online will also be a welcome addition to the literature for practitioners in nephrology. This work may be extended to other chronic conditions in the future, building a comprehensive understanding of how chronically ill individuals seek, share, and disclose personal health information.

This research proposal outlines a dissertation aimed towards understanding how and why people with kidney disease share personal health information in OSGs using a grounded theory approach. The dissertation will add to our understanding of information seeking behavior, disclosure behavior, and social support, and to our knowledge of how these processes are linked.

Research questions

The main research question being investigated in the planned dissertation is:

- What is the process of disclosure? How does it unfold?

There are several sub-questions of interest as well; including, but not limited to:

- What causes people to disclose personal health information online?
- Is there a pattern of disclosure events, or benchmarks that occur throughout the disclosure process?
- Does sharing change over time? If so, how?
- What are the contextual conditions that influence disclosure?
- What facilitates online disclosure?
- Are there obstacles to online disclosure? What are they?
- Do people share different things in different online spaces? Why or why not?
- How does disclosure behavior online compare to disclosure behavior offline?
- What are the outcomes of disclosure?

The purpose of these questions is to develop an understanding of the process of personal health information disclosure in OSGs for kidney patients. It is expected in grounded theory development for research questions to evolve over time as new data is collected. Some of these questions will not be answered by the proposed research, and others will emerge throughout the process.

At this stage in the research, disclosure of personal health information is generally defined as purposeful online sharing of information about one's diagnosis, the lived experience of the disease and/or treatment, and other information that may be found in one's personal health record such as laboratory values, weight and diet specifications, and details about one's emotional well-being and coping strategies. OSGs are defined as Internet-based forums geared towards patients with a specific disease or who are undergoing a specific treatment; in this case, groups for patients with chronic kidney disease or end-stage renal disease of any etiology, groups for patients on dialysis, and/or groups for people who are preparing for or have had a kidney transplant.

Research methods

To investigate these questions, grounded theory (GT) was selected as the research method. The intent of grounded theory is to explain social interactions and to build understandings of social phenomena, resulting in the creation of middle-range theory (Glaser & Strauss, 1967). This project

takes a constructivist approach to grounded theory. It is interpretive and reflective, building theory that explains and demonstrates the complexity of experiences and events (Charmaz, 2006). GT is ideally suited for questions about processes and behaviors in situations where no theory exists, or the models and theories at present "do not address potentially valuable variables of interest to the researcher" (Creswell, 2007, p. 66). All existing relevant theories on information behavior, disclosure, and social support are insufficient to explain the phenomenon in question. Therefore, GT emerges as a potential avenue for developing a theory that addresses the process of personal health information disclosure to a very large online audience.

GT emphasizes simultaneous data collection and analysis in a process known as the constant comparative method, which is at the very core of what distinguishes it from other methods of analysis (Walker & Myrick, 2006). It is a way of collecting and analyzing data nearly simultaneously, described as a dialogue between the data and the ideas being generated by the data (Dey, 1999). Essentially, the researcher analyzes data throughout the collection process; that is, data collection and analysis are interwoven processes in GT, which allows the analysis to change as the research progresses, conforming to fit the data as it is collected (Glaser & Strauss, 1967).

The researcher will conduct interviews and scrape online content from approximately 25 users of OSGs for CKD.[1] The participants must be CKD patients experiencing a self-defined transition in their illness, such as initiating dialysis or recovering from a recent kidney transplant. The initial sample of participants will consist of approximately six members of OSGs for kidney patients, and the rest of the sample will be recruited using theoretical sampling for a total of approximately 25 participants. They will be recruited by replying to recruitment messages posted by the researcher on OSG forums for kidney disease. Two forums have given the researcher

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[1] It is not possible to state the precise number of total informants for this study. Data collection will proceed until theoretical saturation occurs, when each theoretical category has been fully developed and there are no gaps between categories.

permission for recruitment, and several other OSGs will be contacted for permission as the research

progresses.

The researcher will conduct two separate interviews over the telephone with each

participant: the first will focus on health information seeking behavior; the second will be on the

topic of health information sharing and disclosure. In-depth interviews are common data sources in

grounded theory research, particularly in cases where there are likely to be multiple perspectives

on the phenomenon in question (J. M. Johnson, 2002). Each interview will last approximately 60 to

90 minutes. They will be semi-structured in order to allow for unexpected developments and

digressions. Example interview questions include "Why did you decide to go online to learn more

about your health?" and "Has the process of discussing your health online changed over time?"

Two data sources will be gathered online from the OSGs: profile information for each

participant, and all threads where the participants have posted. All OSG data will be gathered using

custom Python scripts and will be stored in a SQL database. The researcher will hire a programmer

to tutor her in basic Python programming and SQL for this portion of the study. The SQL database

will allow the researcher to search and sort by username, date, and keywords in the text of each

post. This data will provide a rich corpus for analysis, complementing the interview data.

After the initial sample has been interviewed, some forum data has been collected, and

theoretical codes, categories, and constructs have begun to emerge, the researcher will use

principles of theoretical sampling in order to recruit subsequent participants. In theoretical

sampling, informants are chosen based on how they may help the researcher explore and expand

themes or gaps between themes identified in the existing data. As Glaser and Strauss explain, "Our

[sampling] criteria are those of *theoretical purpose and relevance*—not of structural circumstance"

(Glaser & Strauss, 1967, p. 48). Put simply, theoretical sampling is the process by which the

researcher chooses data sources with a focus on the analysis that has already taken place. This

allows codes, categories, and constructs to be fully developed until no new properties are present in the data, which is known as theoretical saturation.

In grounded theory, the pre-processing of interviews must take place fairly soon after the interview has been completed so that the constant comparative method may be effectively employed. Once the researcher has transcribed the interviews, she will then begin to compare this data with the data that has already been gathered and analyzed. Then, she will gather forum posts from the interviewee and will analyze this data in the same manner. Both data sources will be analyzed using open coding, "the process of breaking down the data into distinct units of meaning" (Goulding, 1999, p. 9). The researcher will begin by examining each line of the data – for example, an interview transcript or a forum post – and asking herself questions such as "What is this data a study of? What does the data suggest?" (Charmaz, 2006, p. 47), all the while being careful to stay open to emerging ideas. As the analysis progresses, the researcher moves into focused coding, where the codes that have emerged thus far are synthesized and become more conceptual, explaining larger swaths of data. However, this process is not exactly linear: the researcher may move from initial coding practices to focused coding, and even on to theoretical coding – integrating all the codes together into theory – throughout the research process (Charmaz, 2006). As the data collection and analysis progress, codes and categories will be integrated in order to generate the core concepts of the theory. In this phase of the analysis, the researcher will "[answer] the questions of who, when, why, how, and with what consequences . . . to relate structure with process" (Corbin & Strauss, 1998, p. 127).

Data collection and analysis is greatly informed by memoing, which occurs throughout the research process. Memos are documents that outline the codes, categories, and constructs as they are being constructed; they also track the research process itself. Glaser and Strauss (1967) advocate writing memos in the field, during data collection; Charmaz promotes a similar approach, using words like "jotted" and "scribbled" (2006, p. 75) to emphasize their informal nature. In fact,

she later says that ideally, memos should be spontaneous and freeform, because this allows for gaps and probes about the data to emerge. Memoing aids the researcher in identifying gaps where theoretical sampling will be useful, helps to bolster emerging categories and constructs. It also provides an outlet for the researcher to explicate and keep track of the research process. Finally, memoing guides theoretical sampling, as it aids the researcher in identifying gaps that will then be systematically filled via theoretical sampling. Memos are also useful for assessing the trustworthiness of the generated theory.

Trustworthiness in qualitative research is assessed by determining whether the research is credible, transferable, dependable, and confirmable (Lincoln & Guba, 1985). Many methods will be used to assess trustworthiness in this study, including member checking, peer debriefing, negative case analysis, and data audits. Member checking is the process of discussing the emerging codes, categories, and theoretical constructs with the participants. The researcher will create a one- to two-page bulleted list of notes from each interview; these notes will be sent to the participant within two weeks after the interview was conducted, along with instructions to contact the researcher if any of the notes need clarification. A list of quotes from the interviews and forums will also be sent to each participant prior to publication for approval as an additional member check.

Peer debriefing, or the process of discussing the coding process and the emerging theory with peers (such as an academic advisor, dissertation committee, and other doctoral students) will also be used to confirm credibility. Negative case analysis will also be employed, wherein the researcher checks the data for any information that contradicts the emerging codes, categories, and constructs. If data that contradicts the theory is found, the codes, categories, and constructs are re-worked in order to accommodate the negative case (Brodsky, 2008). This process will be documented in researcher notes, establishing part of the audit trail, along with interview notes, transcripts of follow-up interviews conducted as part of member checking, and notes from peer debriefing meetings with the researcher's advisor and other doctoral students.

Data audits will also be employed to assess the trustworthiness of the theory. The continuous creation of memos throughout the GT process provides an audit trail so that the researcher and other interested parties can check both the dependability and confirmability of the results. The researcher will keep notes on the research process itself that may not be present in the memos, such as challenges she faces in data collection and analysis that are not particular to any specific code or category, although not all memos have to be code or category specific. Formal audits will then be conducted on the theory by a third party that assess the appropriateness of inquiry decisions, methodological shifts, the degree of researcher bias, the logic of inferences, and whether the researcher accounted for discrepant data (Schwandt & Halpern, 1988).

After the trustworthiness of the theory has been verified, the researcher will write the theory. Charmaz (2006) recommends that the generated theory should be credible, original, have resonance, and be useful. These criteria essentially echo Morgan and Wildemuth's (2009) assertion that new theory should be surprising, providing us a new way of looking at the world. Charmaz lays out a series of questions that the researcher should ask of her generated theory in order to determine if it meets these criteria, including questions such as "Do your categories offer new insights?" and "Does your analysis offer interpretations that people can use in their everyday worlds?" (2006, pp. 182–183). These questions will be asked throughout the research process and addressed in memos in order to evaluate the generated theory. The written theory will offer a fresh perspective on the process of online health information seeking and disclosure in OSGs for kidney disease. This theory can then be tested for other types of health information disclosure in order to expand our understanding of how and why people search for and share personal health information in a variety of contexts. Additionally, this work will be useful for many types of researchers and practitioners, including but not limited to information scientists, online support group moderators, and healthcare providers, all of whom will benefit from a clearer, more robust understanding of the process of personal health information disclosure online.

B. Schedule of completion

I will be using grounded theory in my dissertation research. In grounded theory, data is collected and analyzed simultaneously, and this does not cease until theoretical saturation is achieved. Grounded theory relies on continuous testing of the theory as it is constructed from the theoretically sampled data via the constant comparative method. The process is recursive and difficult to document linearly; therefore, constructing a timeline is challenging.

Based on the experiences of other grounded theory researchers, I anticipate that this project will take approximately a year and a half to complete. Major milestones include:

- Initial sampling (begins July 2013)
- Begin scraping forum data (begins July 2013)
- Initial interviews (complete by September 2013)
- Theoretical sampling (begins September 2013)
- Integrating codes, categories, and constructs (begins September 2013)
- Data audits to verify theory trustworthiness (January 2014; December 2014)
- Theoretical saturation achieved (complete by December 2014)
- Writing the theory (complete by February 2015)

The dissertation proposal was defended and accepted by the committee on April 15, 2013. The IRB documentation was approved in June 2013, and recruitment will begin the first week of July 2013.

C. Budget

Item	Cost	Amount	Total
A. Incentives for participants	$25/participant	25 participants	$625
B. Training for scraping forum data from online support groups	$25/hour	35 hours	$875
		Total	$1500

A. The researcher is offering $25 to participants as a token of appreciation for their time.

There will be approximately 25 participants total, although the exact number is not yet

known and will not be finalized until the researcher achieves theoretical saturation (see

attached proposal). Each participant will spend between 2 and 3.5 hours on the study, and a

monetary token of appreciation is appropriate for their willingness to devote time to this

project. If there are more than 25 participants, the researcher will fund the remaining

incentives with personal money.

B. The researcher needs training in basic Python and SQL in order to scrape and manage

participant data gathered from online support groups. The tutor charges $25/hour, and

estimates that the training and work will take 35 hours total. If the training takes more than

35 hours, the researcher will fund the remaining time with her personal money.

D. Other funding sources

I will be employed as a teaching assistant at the University of North Carolina at Chapel Hill

in the School of Information and Library Science during the 2013-14 school year. I will be teaching

INLS500, Human Information Interactions in the Fall semester and INLS513, Consumer Health

Information in the Spring semester. Both of these are master's courses. This is my only source of

funding.

E. Dissertation advisor

My faculty advisor and the chair of my dissertation committee is Dr. Barbara Wildemuth,

Associate Dean for Academic Affairs and Professor at the University of North Carolina at Chapel

Hill's School of Information and Library Science.

References

Attrill, A., & Jalil, R. (2011). Revealing only the superficial me: Exploring categorical self-disclosure online. *Computers in Human Behavior*, *27*(5), 1634–1642. doi:10.1016/j.chb.2011.02.001

Barak, A., & Gluck-Ofri, O. (2007). Degree and reciprocity of self-disclosure in online forums. *Cyberpsychology & Behavior: The Impact of the Internet, Multimedia and Virtual Reality on Behavior and Society*, *10*(3), 407–417. doi:10.1089/cpb.2006.9938

Belkin, N. J. (1980). Anomalous states of knowledge as a basis for information retrieval. *Canadian journal of information science*, *5*(1), 133–143.

Case, D. O. (2012). *Looking for Information: A Survey of Research on Information Seeking, Needs and Behavior* (3rd ed.). Emerald Group Publishing.

Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis* (1st ed.). Sage Publications Ltd.

Chuang, K. Y., & Yang, C. C. (2010). Helping you to help me: exploring supportive interaction in online health community. In *Proceedings of the 73rd ASIS&T Annual Meeting on Navigating Streams in an Information Ecosystem - Volume 47* (pp. 9:1–9:10). Pittsburgh, Pennsylvania: American Society for Information Science.

Corbin, J. M., & Strauss, A. C. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (3rd ed.). Sage Publications, Inc.

Coresh, J., Selvin, E., Stevens, L. A., Manzi, J., Kusek, J. W., Eggers, P., … Levey, A. S. (2007). Prevalence of chronic kidney disease in the United States. *JAMA: The Journal of the American Medical Association*, *298*(17), 2038–2047. doi:10.1001/jama.298.17.2038

Coresh, J., Stevens, L. A., & Levey, A. S. (2008). Chronic kidney disease is common: what do we do next? *Nephrology, Dialysis, Transplantation: Official Publication of the European Dialysis and Transplant Association - European Renal Association*, *23*(4), 1122–1125. doi:10.1093/ndt/gfn117

Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches*. Sage Publications, Inc.

Dervin, B. (1998). Sense-making theory and practice: an overview of user interests in knowledge seeking and use. *Journal of Knowledge Management*, *2*(2), 36–46. doi:10.1108/13673279810249369

Dey, I. (1999). *Grounding grounded theory*. Academic Press San Diego, CA.

Eichhorn, K. C. (2008). Soliciting and Providing Social Support Over the Internet: An Investigation of Online Eating Disorder Support Groups. *Journal of Computer-Mediated Communication*, *14*(1), 67–78. doi:10.1111/j.1083-6101.2008.01431.x

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ*, *328*(7449), 1166. doi:10.1136/bmj.328.7449.1166

Ferguson, T., & Kelly, W. J. (1999). E-patients prefer e-groups to doctors for ten of twelve aspects of health care. *Ferguson Report*, *1*, 1–3.

Fox, S. (2011a). The social life of health information, 2011. *Retrieved July*, *7*, 2011.

Fox, S. (2011b). *Peer-to-peer healthcare*. Washington, D.C.: Pew Research Center's Internet & American Life Project. Retrieved from http://www.pewinternet.org/Reports/2011/P2PHealthcare.aspx

Glaser, B. G., & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: NY: Aldine de Gruyter.

Godbold, N. (2010). "Come back and post often": making sense of renal dialysis via online discussion boards. Presented at the British Sociological Association's Medical Sociology Group Annual Conference, Durham, UK.

Gollop, C. J. (1997). Health information-seeking behavior and older African American women. *Bulletin of the Medical Library Association*, *85*(2), 141.

Goulding, C. (1999). Grounded theory: Some reflections on paradigm, procedures and misconceptions. Retrieved from http://wlv.openrepository.com/wlv/handle/2436/11403

Groome, P. A., Hutchinson, T. A., & Tousignant, P. (1994). Content of a Decision Analysis for Treatment Choice in End-stage Renal Disease. *Medical Decision Making*, *14*(1), 91 –97. doi:10.1177/0272989X9401400111

Harwood, L., Locking-Cusolito, H., Spittal, J., Wilson, B., & White, S. (2005). Preparing for hemodialysis: patient stressors and responses. *Nephrology Nursing Journal*, *32*(3), 295–303.

Hesse, B. W. (2005). Trust and Sources of Health Information: The Impact of the Internet and Its Implications for Health Care Providers: Findings From the First Health Information National Trends Survey. *Archives of Internal Medicine*, *165*(22), 2618–2624. doi:10.1001/archinte.165.22.2618

Iles-Smith, H. (2005). Perceptions and experiences of pre-dialysis patients. *EDTNA/ERCA Journal of Renal Care*, *31*(3), 130–133.

Johnson, J. D., & Case, D. O. (2012). *Health Information Seeking* (First printing.). Peter Lang Publishing.

Johnson, J. M. (2002). In-depth interviewing. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of Interview Research: Context & Method* (pp. 103–119). Thousand Oaks, CA: Sage Publications.

Klang, B., Björvell, H., & Clyne, N. (1999). Predialysis education helps patients choose dialysis modality and increases disease-specific knowledge. *Journal of Advanced Nursing*, *29*(4), 869–876. doi:10.1046/j.1365-2648.1999.00957.x

Kuhlthau, C. C. (1993). A principle of uncertainty for information seeking. *Journal of Documentation*, *49*(4), 339–355.

Lenz, E. R. (1984). Information seeking: A component of client decisions and health behavior. *Advances in Nursing Science*, *6*(3).

Lewis, A. L., Stabler, K. A., & Welch, J. L. (2010). Perceived informational needs, problems, or concerns among patients with stage 4 chronic kidney disease. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*, *37*(2), 143–148; quiz 149.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry* (1st ed.). Sage Publications, Inc.

Martin, S. C., Stone, A. M., Scott, A. M., & Brashers, D. E. (2010). Medical, Personal, and Social Forms of Uncertainty Across the Transplantation Trajectory. *Qualitative Health Research*, *20*(2), 182 –196. doi:10.1177/1049732309356284

Morgan, C., & Wildemuth, B. M. (2009). Questions related to theory. In *Applications of social science research methods to questions in information and library science* (pp. 40–47). Westport, CT: Libraries Unlimited.

Ormandy, P. (2008). Information topics important to chronic kidney disease patients: A systematic review. *Journal of Renal Care*, *34*(1), 19–27.

Orsino, A., Cameron, J. I., Seidl, M., Mendelssohn, D., & Stewart, D. E. (2003). Medical decision-making and information needs in end-stage renal disease patients. *General Hospital Psychiatry*, *25*(5), 324–331.

Savolainen, R. (2006). Information use as gap-bridging: The viewpoint of sense-making methodology. *Journal of the American Society for Information Science and Technology*, *57*(8), 1116–1125. doi:10.1002/asi.20400

Schwandt, T. A., & Halpern, E. S. (1988). *Linking Auditing and Metaevaluation*. Thousand Oaks, CA: SAGE Publications.

Van Uden-Kraan, C., Drossaert, C., Taal, E., Seydel, E., & Van De Laar, M. (2009). Participation in online patient support groups endorses patients' empowerment. *Patient Education and Counseling*, *74*(1), 61–69.

Veinot, T. C. E., Meadowbrooke, C. C., Newman, M. W., Zheng, K., & Perry, E. E. (2010). Routines that ease the pain: The information world of a dialysis clinic. *Proceedings of the American Society for Information Science and Technology*, *47*(1), 1–4.

Walker, D., & Myrick, F. (2006). Grounded theory: An exploration of process and procedure. *Qualitative Health Research*, *16*(4), 547–559.

Wilson, T. D. (1997). Information behaviour: an interdisciplinary perspective. *Information Processing & Management*, *33*(4), 551–572.