

RUNNING HEAD: Surrogates and Proxy Ownership

Surrogate Decision Makers and Proxy Ownership:  
Challenges of Privacy Management in Health Care Decision Making

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This is the author's manuscript of the article published in final edited form as:

Bute, J. J., Petronio, S., & Torke, A. M. (2015). Surrogate decision makers and proxy ownership: challenges of privacy management in health care decision making. *Health Communication*, 30(8), 799–809.

<http://doi.org/10.1080/10410236.2014.900528>

**Abstract**

This study explored the communicative experiences of surrogates who served as decision makers for patients who were unable to convey health information and choices about treatment options. Drawing on assumptions from communication privacy management theory (Petronio, 2002), 35 surrogates were interviewed to explore how they navigated the role of guardian of patients' private health information while the patient was hospitalized. This research determined that surrogates are not only guardians and thereby co-owners of the patients' private health information, they actually served in a "proxy ownership" role. Surrogates described obstacles to both obtaining and sharing private health information about the patient, suggesting that their rights as legitimate co-owners of the patients' information were not fully acknowledged by the medical teams. Surrogates also described challenges in performing the proxy ownership role when they were not fully aware of the patient's wishes. Theoretical and practical implications of these challenges are discussed.

Key words: Health care surrogates, decision-making, Communication Privacy Management, private information ownership

## **Surrogate Decision Makers and Proxy Ownership:**

### **Challenges of Privacy Management in Health Care Decision Making**

As many as 47% of patients in the hospital are partially or completely unable to communicate or make medical decisions due to serious acute illness such as trauma or stroke, chronic conditions like dementia, or sedation given in the hospital (Torke et al. 2013). Such incapacity is especially common among older adults and likely to increase as the population ages and diseases like dementia become more prevalent (Alzheimer's Association, 2011). In cases when a patient has a communication-debilitating illness or injury, family members or others close to the patient serve as surrogates for the patient (Bute, Donovan-Kicken, & Martins, 2007; Torke, Simmerling, Siegler, Kaya, & Alexander, 2008). Surrogates must provide crucial health and personal information to clinicians and are frequently asked to participate in making medical decisions on the patient's behalf. This role requires a complex exchange of information involving the surrogate, clinicians, and the patients, if they retain some capacity to communicate.

Unfortunately, there is growing evidence of poor surrogate-clinician communication (Torke et al., 2012a). Surrogates' experiences with palliative and end-of-life care decisions are often marked by dissatisfaction with clinician communication and decision making processes (Baker et al., 2000; Teno et al., 2004). Further, surrogates' medical encounters are typically characterized by communication that is highly fragmented: surrogates report engaging in brief and infrequent conversations with large numbers of clinicians, including various physicians, specialists, and nurses. As a result, surrogates are rarely able to develop personal relationships with patients' health care providers (Torke, Siegler, Abalos, Moloney, & Alexander, 2009). These experiences likely explain why surrogates have expressed a desire for frequent contact

with clinicians, better access to information about the patient, and emotional support from health care providers (Torke et al., 2012a).

Gaining a better understanding of surrogate-clinician interactions is imperative, given that the quality of the communication between surrogates and clinicians is linked to a host of important outcomes for both the patient and the surrogate. Evidence suggests that surrogates faced with caring for a critically ill family member can experience symptoms of post-traumatic stress disorder that are heightened when there is poor communication with providers (Azoulay et al., 2005). The state of the surrogate is an important component in the type of care the patient receives. As such, learning more about how the surrogate navigates communicating with the clinician and medical team becomes a primary key in effective health care delivery to the patient. Given the increased needs of an aging population, determining best practices for surrogate-clinician communication is essential (Torke, Petronio, Sachs, Helft, & Purnell, 2012b).

One aspect of surrogate-clinician medical encounters likely crucial to good decision making and ethical treatment is the management of private information (Petronio, Di Corcia, & Duggan, 2012). The exchange of private health information between surrogates and health care providers is a vital part of providing patient care for individuals unable to make independent decisions about health care options. For instance, recent work by Torke, Petronio, Sachs, Helft & Purnell (2012b) suggests that the quality of health care decisions made by surrogates is linked to information disclosure to and from clinicians, but we know little about how surrogates experience these sorts of interactions. At the same time, clinicians often rely on surrogates for access to private health information about the patient. Using the lens of Petronio's (2002) Communication Privacy Management theory, this research investigates the way surrogate

decision makers manage private health information for hospitalized, incapacitated patients during the course of patient care.

### **Communication Privacy Management and the Role of Surrogates**

Communication Privacy Management (CPM) is an evidenced-based theory developed to understand the complexity of how people manage private information (Petronio, 2013). CPM proposes individuals “consider private information something they own, and over which they desire control” (Petronio, 2002, p. 9). This type of information tends to be reflective of issues for which there is a certain level of perceived vulnerability, such as private medical information.

People exercise ownership rights through the management of privacy boundaries that vary in their levels of permeability. The boundary metaphor symbolizes the way people mark the information as private and helps to illustrate the way people regulate granting and denying access to the private information. The regulation of these privacy boundaries concerning who can know, how much others can know, and the level of control granted is accomplished through the use of privacy rules. Once someone is allowed to know the private information, there is an expectation that they too will follow privacy rules for third-party access.

CPM argues that when people are granted access to private information, their role shifts and they become co-owners of someone else’s information. As a co-owner, there are responsibilities and expectations held by the original owner for the handling of that person’s private information. Co-owners may be expected to manage another’s private information in particular ways. For example, co-owners can find that they are duty-bound to fulfill an “obligatory co-ownership” role where the owner needs someone to help them manage their private information (Petronio, 2002, p. 131).

Besides an obligation of co-ownership, the surrogate role is unique, in that, original owners cannot provide guidance about the privacy rules they want the surrogates to use concerning their private health information. As such, the role of surrogate is more closely aligned with serving as a “proxy” or agent for the patient in communicating with clinicians, making health care decisions, and coordinating the patient’s private information. Thus, “proxy ownership,” where private information is concerned, reflects not only fulfilling the obligation to be a co-owner, but also judging the way a patient might want his or her private information managed. As this description suggests, surrogates often face complicated challenges.

First, surrogates’ knowledge of patient preferences may vary widely. There are times when surrogates have been selected prior to a medical crisis and are privy to health information, including preferred choices of treatments. On the other end of the spectrum, there are circumstances where surrogates are called in without knowing anything about the patient’s medical issues or preferences. Second, patients depend on surrogates to perform a crucial role in health care at a time where the patient has little control. Thus, the patient’s medical care is in the hands of the surrogates, as the medical staff is serving the patient through the surrogate.

Third, surrogates often are the primary source of information about patient medical issues and are likely to be called upon to make decisions regarding treatment options and other judgments to accomplish patient care. Accordingly, surrogates perform a critical role whether the patient designated them as their representative or they agreed to serve as surrogates because they are the only ready option to help the patient in need. Fourth, when the surrogates serve in this role, there is evidence to suggest that clinicians may not recognize the responsibilities and stress of guardianship for communicating the patient’s information (Torke et al., 2012a).

As these issues indicate, the surrogate is often situated in dilemmatic circumstances trying to care for patients who are unable to articulate their privacy rules for disclosing medical information (Petronio & Sargent, 2011; Petronio, Sargent, Andea, Reganis, & Cichocki, 2004). They also may not know the patient's desires for treatment options and could be coping with the clinical staff who may neglect the importance of the role they are trying to play in patient care. At tension in these dilemmas is the question about information ownership rights and the center of control over that information. These circumstances characterizing surrogate dilemmas are best defined as situations where both the surrogate and clinical staff contend for recognition that they have the rights of ownership on behalf of the patient (Petronio, 2013).

As CPM research shows, patients feel rights of ownership over health information and expect that physicians will disclose information to them (Helft & Petronio, 2007; Petronio, et al, 2012). Likewise for surrogates enacting a proxy ownership role, they have to claim rights of ownership over the patient's health information, even though it is not their own health that is at stake. As informational guardians, surrogates expect clinicians to share the patient's health information with them (Torke et al., 2012b). However, while clinicians assume that the surrogate will provide patient information to them, the clinicians do not always recognize that they expect the flow of information as one way from surrogate to clinician.

Moreover, privacy rules used to regulate access and protection of private information are predicated on a certain set of contextual criteria (Petronio, 2013). CPM theory that choices about the way privacy boundaries are regulated and influence the flow of information often depend on the context in which disclosure or protection occurs (Petronio, 2002, 2013). For instance, conversations between surrogates and clinicians take place in a broader institutional and legal context. Thus, these interactions are best understood when attention is paid not only to facets of

the interpersonal relationships involved but also to the cultural, legal, and organizational forces that shape the management of private information (Street, 2003). For instance, in medical facilities, clinicians are concerned about the Health Insurance Portability and Accountability Act (HIPAA), in particular, the Privacy Rule, which regulates the sharing of private health information (Department of Health and Human Services, 2013). Although HIPAA does not preclude clinicians from informing surrogates about a patient, (Levine, 2006), some health care providers have expressed uncertainty about the constraints that the law imposes on information sharing, such as what specific information can be shared and with whom (Stone, 2013).

This application of CPM theory suggests that both the interpersonal and contextual issues of privacy management have an impact on the way surrogate decision makers carry out their role when caring for hospitalized, incapacitated patients. Because surrogates are now and will become even more needed members of a health care environment with a progressively aging population and because private health information is an integral part of surrogate effectiveness, this investigation explores the privacy management issues that impact the surrogates' ability to perform their decision making role as proxy owners.

RQ1: How do surrogate decision makers navigate serving as proxy owners in a hospital setting when they care for incapacitated, hospitalized patients?

## **Methods**

### **Study Design and Population**

The methods of this study were approved by a Midwestern university institutional review board. For the purposes of the project, a surrogate was defined as a person who made at least one major decision in the hospital on behalf of a patient who was unable to do so. Although



some of these surrogates may have played a caregiving role outside of the hospital, surrogates where defined in this study according to their roles as decision-makers.

To explore surrogate-clinician communication, we conducted interviews with surrogates at two hospitals affiliated with a large medical school: an urban, public hospital and a university-affiliated tertiary care referral hospital. The interviews were part of a larger observational study of the process and outcomes of surrogate decision making. To recruit participants, researchers used the electronic medical record to identify patients 65 and older admitted to the medicine and medical intensive care unit (ICU) services of the hospitals. During the admission, a research assistant consulted with the patient's hospital physician to identify patients who required at least one major decision during the first 48 hours of hospitalization, defined as decisions involving: life sustaining care (e.g., code status, ventilation, and artificial nutrition), procedures and surgeries requiring informed consent, or nursing home placement. We then asked physicians to identify patients for whom a surrogate participated in the decision. We included patients for whom the surrogate made all decisions and patients who required surrogate involvement but were partially able to participate in communication and decision making. In each case, the patient's primary attending physician was asked if the patient was capable of giving informed consent for research participation at the time of enrollment. If yes, consent was obtained from the patient as well as the surrogate. However, the majority of the surrogates in the sample represented a patient who did not have and never regained full decision-making capacity. The surrogates were contacted by phone or at the bedside to request their participation in the study.

Interviews were initially conducted with surrogates from both the medical inpatient units and medical ICU. In our preliminary analysis, we found that the most difficult communication appeared to revolve around life sustaining therapy decisions in the ICU. Specifically, we found

examples of conflict, surrogate distress, and surrogate dissatisfaction with communication.

Based on this finding, we focused subsequent interviews on participants in the ICU setting, and used purposive sampling (Lindlof & Taylor, 2002).

Based on consultations with 835 physicians, we identified 595 patients who required at least one major decision. Of these, 253 patients had a surrogate decision maker and 100 out of 253 were successfully contacted and consented to enrollment in the larger prospective study. We were able to successfully complete semi-structured interviews with 35 out of 100 surrogates to explore the topic of the present paper. Most of the surrogates we interviewed were women ( $n = 28$ ) and were daughters of the patient ( $n = 21$ ). About half of the participants were African American ( $n = 18$ ), and the rest were White ( $n = 17$ ; see Table 1 for additional demographic information). Thirteen interviews were conducted regarding decisions in the ICU. Seven of these were conducted after making the decision to focus interviews on the ICU setting. The mean duration of interviews was 40 minutes (range 13-85). Mean time from hospital admission to the interview was 23.2 days (range 4 days - 31 days) for patients who survived. For decedents, mean time from death to interview was 110.0 days (range 107 days - 142 days). The 35 participants faced a total of 66 decisions (also see Table 2).

### **Data Collection**

Interviews were conducted by one of two interviewers in a hospital conference room or the surrogate's home. Prior to the interview, written informed consent was obtained from each surrogate. Because of the potential for recall bias, we sought to interview surrogates during or soon after the patient's hospitalization. We conducted interviews between 48 hours and one month from the hospital admission. If the patient died prior to the interview, we conducted the

interview two-five months after the patient's death, a time interval similar to those in other after-death family interviews (Mitchell et al., 2006).

The semi-structured interview guide was based on a conceptual model of surrogate decision making developed by Torke and Petronio (Torke et al, 2012b). The interview guide contained questions focused on conversations with clinicians and specific questions about the major decisions made by surrogates, followed by a series of optional prompts to further explore the topics. The recruitment method and interview guide were pilot tested with seven surrogate decision makers and refined prior to the start of the study.

### **Data Analysis**

Based on principles of rigorous qualitative inquiry (Charmaz, 2006) and guided by CPM theory, we followed an iterative process for data analysis (Strauss & Corbin, 1990). In round one of analysis, the first author, with expertise in issues of privacy management, undertook an in-depth reading of all 35 transcripts to establish a holistic sense of the data and identify privacy-related issues that emerged from this initial reading. Portions of the transcripts were highlighted focusing on relevant issues of privacy management to determine the primary themes that captured concepts germane to CPM theory. Based on the findings of this initial step, the authors collaborated to discuss and develop a preliminary set of primary themes that described the privacy management challenges identified by surrogates. Next, the authors re-read a subset of the transcripts to verify and refine the initial themes. A random numbers generator was used to select ten transcripts. The first two authors each independently coded five of these ten transcripts, coding for the preliminary set of primary themes outlined in round one and determine potential secondary themes that provided information allowing for determining specific conditions of privacy regulation (for both the surrogates and their observations of

clinicians). The researchers verified the primary themes found in the data that represented privacy management issues for these surrogates. The same system to verify the emergence of the secondary themes followed and in the final phase of analysis the researchers examined the entire set of transcripts once more to identify any needed refinements and exemplars for the existing primary and secondary thematic categories.

## **Results**

As surrogate decision makers enact the rights and responsibilities of proxy ownership, they need to manage a complex and multi-faceted process of obtaining, sharing, and managing private health information on behalf of the incapacitated patient. In this regard, surrogates function as proxy owners of the patient's private health information. To better understand the way in which surrogates enact their role as proxy owners of patients' private information, these data show three primary themes that reflect the way proxy ownership among surrogate decision makers is defined within a hospital setting: (a) expectations for access to private information, (b) demands for providing patient information to clinicians, and (c) contextual features relevant to proxy ownership. For each of the themes, the data show a number of secondary themes that establish specific ways that surrogates engage in privacy management on behalf of the patient.

### **Expectations for Access to Private Health Information**

CPM theory argues that in health care settings, people engage in interactions with health care providers having expectations for the level of guardianship over the way their private health information is treated (Petronio et al., 2012). Likewise, there is an expectation that the level of permeability allowing flow of information from patients to providers and from providers to patients is required health care delivery. Surrogates in our study were operating from similar

expectations in their roles as proxy owners. The data reveal four secondary themes that explicate the expectations for access to private health information in this context.

*Presumption of access.* One way that surrogates navigated their ownership responsibility was by projecting their personal privacy rules onto the patient's information. They often viewed the patient's private health information as akin to their own. As a surrogate making decisions for his father explained,

But the big thing, the major thing was communication. It was just...it was as if this was supposed to be a secret. And I know that doctors are really...they don't want you to see your own file. Excuse me! It's me! And I paid you for that! But you know, they're really reluctant to kind of let you get into the stuff. And, I think that they've become a little too protective. But...communication could go a long way. A long way.

The surrogate's language indicates that he is treating the patient's information as though it was his own, which suggests one of the defining characteristics of proxy ownership. Surrogates in this study viewed themselves as rightful owners of the patient's private health information and expected full access to this information. At times, they were stunned to discover that clinicians formed thick boundaries around the patient's information, limiting their access. The presumption of full access illustrates the degree to which surrogate decision makers supplant their own privacy rules for that of the patient's to the extent that they may see no difference between what belongs to them and what information is owned by the patient. Thus, some surrogates considered being barred from access to the patient's private health information akin to being barred from access to their own health information.

*Working to get information.* Although surrogates presume access to patient's private health information, they soon discovered that acting as a surrogate decision maker often demands

working and strategizing to obtain information about the patient. Getting information can frequently involve what might seem like mundane tasks, such as making phone calls to the hospital to check in on the patient or staying with the patient at the hospital. However, even relatively mundane tasks can become taxing for surrogates. Many participants struggled to balance their daily responsibilities with spending time at the patient's bedside. Some described driving to the hospital after work, staying with the patient for a few hours, driving home to make dinner for the family, and then returning to the hospital until bedtime. Surrogates made space in their daily schedules to be present with the patient so that they could support them in a time of need. They were also highly concerned about being present so they could get information firsthand from health care providers; thus, the tension between presence and absence resulted in emotional and physical labor for the surrogates. One surrogate caring for her mother explained:

We didn't always seem to catch the doctors in there. They seemed to get there either super early or at times maybe when we weren't there, and I would say we were there a good majority of the time...I only interacted with her main doctor, I think it was once, from her main team.

Although the surrogate felt that a family member was with her mother the "majority of the time," she still found it challenging to speak to her mother's physician in person. Another woman whose job obligations prevented her from being at the hospital said that she called and spoke with her mother's nurses "four-five-six times a day" to stay updated on her mother's condition.

In some cases, surrogates had to advocate for their right to information or communicate with health care professionals in an assertive manner to get the information they wanted and needed. At times respondents needed to legitimize their role and persuade health care professionals that they had a right to access the patient's information. One man explained that

information was shared “haphazardly,” giving him the impression that he was not getting the full story about the patient’s condition. He sensed that providers seemed to question the authenticity of his co-ownership role. As a strategy to overcome this issue, he detailed his efforts to dress in particular ways (e.g., dressing up instead of wearing casual clothes) and to use “firm but polite” language with clinicians to assert his rights to the information.

Because the surrogates interfaced with a team of health care providers, there was a necessity to coordinate the medical information among all the stakeholders to arrive at a clear understanding of the medical issues for the patient. The following excerpt illustrates the “work” involved in accessing private information from multiple clinicians:

I think they told me they did some x-rays or something but I don’t know how they come up with that and then I’ve been trying to get in contact with the senior care doctor and stuff to just see why are they giving her that because they were supposed to be out the next day to go over with the medicine because when she got released the first time the nurse that was on duty left before we got there so she passed the message on to the next nurse and then that nurse didn’t know that much about it.

Although many of the participants engaged in considerable effort to ensure their access to patient’s private health information, many also had good experiences with providers who recognized their needs for information and were proactive in disclosing updates to the surrogates. As one surrogate recalled:

They explained everything that they were doing and, um, told us, uh, you know, just be patient. We are working on this trying to find out what the, you know, what the problem is... They explained all of the procedures. Everything they was going to do, they came and told us.

Although the health care teams met this particular surrogate's needs for information, there were other situations that challenged the surrogates in this study.

***Delayed information.*** Surrogates' inability to be present at all times often resulted in obtaining private medical information in a delayed timeframe. Because most surrogates were not able to be at the hospital with the patient around the clock, they often received information about the patient's health several hours or even days after an incident had occurred. For example, one woman recalled an incident in which her mother was put on a ventilator while her family was absent from the hospital. The family was not informed until receiving a phone call after the procedure was complete:

He just told me that earlier today we had trouble waking your mom up. She would just open up her eyes and then fall right back to sleep, and nobody ever said well she quit breathing and that's why we ventilated her or her oxygen level was low. We never found out why they ventilated her, what led up to it. We still don't know. So we get the phone call after.

This delay caused confusion for the family and prevented their involvement in decision-making. Such cases highlight the stark contrast between being the patient and being a surrogate who acts on the patient's behalf. A patient who is cognitively aware at the very least knows right away that some sort of incident has occurred or is occurring because that incident is happening to him or her. A surrogate, on the other hand, gets this information in a delayed timeframe.

***Missing information.*** In addition to the other aspects defining a surrogate's expectation for access to information, the nature of proxy ownership also resulted in surrogates getting incomplete or inaccurate private health information about the patient. In one case, the surrogate was asked to leave the room while a team of nurses changed her mother's bandages and



performed other routine tasks. When the surrogate returned to the room, she discovered unexplained bleeding:

So we were like what just happened because 15 minutes ago, all her tubes were clean, and now there is blood in her GI tube. So then at that time, we didn't know if she was bleeding in her stomach, if they ruptured something ventilating her...When they turned her, were they that rough with her that they moved the ventilator around and caused her to bleed?...So then like I said, they ordered a scope to find out. And I guess it just ended up being that they scratched her esophagus and that's where the blood was coming from.

The surrogate's absence from the room combined with trying to gather information from multiple clinicians meant that the patient's family was left with incomplete information and a great deal of uncertainty about a perceived injury that the patient suffered.

As these different dimensions of expectations for information illustrate, surrogates serving as proxy owners encountered a number of specific privacy management issues that challenged their ability to gather needed information to enact the role of surrogate. In the next theme, these data showed the demands for information that come from the medical team.

### **Demands for Providing Patient Information to Clinicians**

Based on surrogates' accounts of their interactions with health care providers, clinicians expected surrogates to be conduits of information about the patient, which is a defining responsibility of proxy ownership. Serving as a conduit was no simple task for the surrogates, and there were situations where there was a disconnection between clinicians' expectations of surrogates' knowledge and the reality of surrogates' knowledge. Moreover, repeating the same information over and over to multiple clinicians was often taxing for surrogates.

*Not knowing the patient's wishes.* Some of the challenges that surrogates faced in fulfilling the proxy owner role centered on the extent to which patients had disclosed certain information to surrogates prior to becoming fully or partially incapacitated. In some cases, surrogates felt they had to make medical decisions on a patient's behalf without a complete understanding of the patient's desires. Surrogates in our study were not always aware whether the patient had a living will, had a desire to be resuscitated, or wished to avoid being put on a ventilator. Nevertheless, in many cases, clinicians expected surrogates to have an intimate knowledge of a patient's final wishes, or even to know information about a patient's bodily functions. For instance, one surrogate described a situation in which the physician repeatedly inquired her about her mother's urine output and appeared frustrated when the surrogate was not able to provide a satisfactory response.

In extreme situations, surrogates described feeling pressured or even forced by health care providers to make decisions without adequate information from the patient. Because these decisions often involved life-saving procedures and end-of-life care issues, surrogates reported feeling anxious and pressured to provide an answer. This was particularly true for surrogates whose loved ones had not disclosed their wishes for palliative care or end-of-life measures. One woman serving as a surrogate for her sister recalled physicians who demanded a decision about whether to resuscitate her sister in a life-threatening situation: "The one thing that they kept pushing and adamantly pushing is that we had to make a decision whether they were going to resuscitate her if anything happened because she was in pretty bad shape." This surrogate, like many others in this study, had never spoken with her sister about her final wishes and found herself forced to speculate about her desires and wishes. In contrast, surrogates who described

having prior conversations with the patients about their requests for care seemed to struggle less with making these difficult decisions.

*Answering to multiple clinicians.* Just as surrogates explained their efforts in working to obtain private information, they also described engaging in “work” as they shared information about the patient with the medical team. A particularly salient feature of medical care for proxy ownership in these situations concerned engaging with multiple care providers who treated the patient. Surrogates found themselves answering to a large number of health care professionals as they communicated the patient’s health information. Some surrogates tired of explaining the same information over and over to each provider they encountered. One participant explained that every conversation with a new nurse, physician, or specialist felt like starting over: “You have to repeat everything multiple times, and it is kind of frustrating because you know you would think, but I don’t know the process that they would just read their medical records... I felt like a tape recorder.” Because clinicians viewed surrogates as owners of the patient’s information, surrogates found they had to be answerable to multiple parties. Yet, as the data on expectations of access demonstrates, surrogates at times felt that those same parties were not always answerable to them.

### **Contextual Features Relevant to Proxy Ownership**

The last theme helps to contextualize the nature of privacy management for surrogate decision makers. Participants’ experiences reported in this study highlighted the ways in which interactions between surrogates and clinicians take place in a broader structural, institutional, and regulatory context. These layers of institutional privacy boundaries have repercussions for surrogate decision makers’ management of private information (Petronio, 2002).

**Rules and policies.** Federal regulations (e.g., HIPAA) that govern the handling of private information are a key aspect of the context in which surrogate-clinician encounters unfold (Street, 2003). Participants frequently mentioned rules and policies that affected their ability to gain private health information about the patient, such as the need to designate “code words” and other practices guiding the sharing of information. Several surrogates mentioned institutional requirements to provide and use a code word, a word designated by the patient’s family and communicated to the hospital, to indicate permission to access the patient’s information. Even when surrogates were able to obtain information from the nursing staff over the phone, doing so was often less than ideal. As one participant explained, “When we would call and ask questions, they didn’t like to give too much information over the phone due (to) privacy...the privacy act.” In this case, it appears that the information was managed by the nurses who may have been following the hospital’s regulatory requirements; nevertheless, the result for this daughter was her sense of being denied access to pertinent information about her mother.

Another woman recalled an exasperating and distressing interaction with a nurse who refused to share updates about her mother’s status with her because the surrogate was not the patient’s designated power-of-attorney (POA):

Um, we did have a nurse that we came into in this unit down here who absolutely was almost hostile to me as I walked in. I mean, it was just...she said, “Are you the POA?” I go, “No, I’m not. I’m one of the daughters.” And I had a cousin sitting in here and she says, “I only talk to the POA.” And I thought, oh, I’m sorry. We’ve not....we’ve been in this hospital for what, two weeks or something. We said, we’ve not had this experience. Nobody has said anything to us about any of this. People have been freely talking to us. Um, and my cousin couldn’t believe it, you know, when she witnessed it. And then, I

mean, during the day, um, I said, “Well, I’m very concerned because I’m going to be the one who’s going to be here for the entire week and you’ve just told me that you’re not going to talk to me and I’m not going to have any resources for getting any information and understanding what’s going on with mom.” And I said, “I need to know what I need to do so that I can get myself into a position.” “There’s nothing you can do.”

Although some surrogates described frustration about these regulatory impediments, many accepted them as part of the process of exchanging information about the patient. As one woman explained, “They had me get the code word and [then] they gave me more information, you know, as to her condition and what was going on.”

*Deciphering hospital systems.* The health care system and the hospital setting, in particular, is designed to meet the needs of a patient who can communicate and who is present to interact with clinicians. Necessary periods of absence from the hospital, which were a persistent theme among our participants, meant that surrogates missed opportunities for face-to-face interactions with clinicians. The tensions between presence and absence described by surrogates highlight the limits of the current hospital system in accommodating the needs of proxy owners.

Other aspects of the organizational context at the hospital also constrained how surrogates managed private information. Patients were often older adults who lived in extended care, rehabilitation facilities, or at times were transferred from one hospital to another. Each entity had privacy rules and different definitions of privacy boundary parameters pertaining to that facility. As a result, the surrogates had to become “boundary coordinators” (Petronio, 2002) among the different levels and kinds of privacy boundaries within these health care facilities.

Surrogates also observed that there was variability in the hospital units they dealt with, noting some offered more or less access to patient information. For example, several surrogates

felt that they received better and more reliable information in the emergency room than they did when the patient was transferred to a more permanent room in the hospital. The following exchange illustrates how the flow of information varied within a given hospital:

...it was a little harder to get people to talk to you than it was on the other floor, I thought. A little longer, or, you know, when you wanted to get someone, you know, it was...took a little longer or they just didn't seem to be as, you know, run to your every move.

A final feature of the hospital context impacting surrogates' privacy management was the inability of nurses to communicate certain private health information to surrogates (Petronio & Sargent, 2011). Even though nurses play an important role in helping surrogates, the organizational context that often prevails hampers the nurses' ability to provide needed private information for successful surrogate decision making (Torke, Sachs, Helft, & Petronio, 2008). The hierarchy, power dynamics, and legal constraints of the health care system, as well as differences in expertise often mean that nurses cannot fully answer questions and concerns of the surrogates. Surrogates in this study were well aware of this challenge: "And if you asked questions, they [the nurses] would answer you the best that they could. I know there is some stuff that they can't say. You know, it has to come from a doctor." Previous studies underscore this problem, for example, nurses have expressed interactional dilemmas stemming from limitations on what they can share with surrogates (Stone, 2013). The various contextual criteria resulted in clear consequences for the ways in which surrogates handled patients' private health information in the hospital setting.

## **Discussion**

The goal of this study was to discover the challenges surrogate decision makers have as they enact a proxy ownership role managing private health information on behalf of patients. As they perform this sometimes unexpected and often stress-inducing role, they must navigate a complex hospital system that complicates their efforts to manage patients' private health information. Moreover, the extent to which surrogates feel comfortable in this role varies widely, as does their ability to fulfill the associated responsibilities. These variations often depend on issues such as the surrogate's knowledge of the patient's health history, familiarity with the patient's wishes concerning health care decisions, and the cooperation of the clinicians in treating the surrogates as fully-authorized proxy owners of information. The interpersonal context of surrogate decision making differs in important ways from direct medical encounters between the patient and clinicians. We found that acting as a surrogate requires navigating proxy ownership of the patient's information by the clinicians and the surrogate. Unfortunately, our data indicate that clinicians and surrogates often have divergent views of this ownership role.

As surrogates sought access to information, tried to provide health information requested by the clinicians, and asserted their rights of proxy ownership over the patient's information, surrogates found they had to work harder than they expected. Many surrogates assumed they would have easy access to patients' information. They were often frustrated when information was delayed or incomplete due to complex organizational structures and lack of effective communication among multiple care providers. Moreover, surrogates reported having to work to convey the same information over and over to various clinicians. They also encountered a sense of violating clinicians' expectations when they were unable to provide particular information, such as a patient's wishes for palliative care or life-saving measures.

As these issues suggest, the surrogate is often situated in dilemmatic circumstances trying to care for patients who may not be able to articulate their desires, at times not knowing the best course of action for medical treatments, and coping with the clinical staff who may ignore the importance of the role they are trying to play in patient care. At tension in these dilemmas is the question about information ownership rights and the center of control over that information. The circumstances that surrogates find themselves in are situations where there is a vying for informational control with the clinical staff and misunderstood parameters of information ownership on behalf of the patient.

From a theoretical standpoint, our data suggest that both surrogates and clinicians expect relatively permeable boundaries around the patient's private health information (Petronio, 2002). Surrogates presume to be fully informed of the patient's current condition, any treatments or procedures that have been performed, and the patient's projected prognosis. Likewise, clinicians assume surrogates have and readily will share information about the patient's desired course of action, especially when drastic measures might be required to sustain or prolong a patient's life. However, these expectations for permeable boundaries are often violated. Surrogates might have to work hard to assert their ownership of the information, even if they have a legitimate right and need to be treated as co-owners. Further complications might arise when multiple family members want access to information, such as cases in which a family member is involved in decision making but has not been appointed as the legally-designated POA. What our interviews suggest is that clinicians and health care organizations might create and enforce unnecessarily thick boundaries that make it difficult for surrogates to get the information they need to make sound health care decisions. In some situations, clinicians are likely to have the best of intentions in following institutional policies when they require surrogates to provide code words



or refuse to disclose information to certain family members. However, clinicians and hospitals might also unintentionally create a perception of thick, rigid boundaries around information when they resist sharing information, or when they share inconsistently, incompletely, or in a delayed time frame (also see Torke et al., 2012a).

Our data also suggest that clinicians expect to gain access to private information about the patient's wishes through conversations with surrogates. This expectation is perhaps most clearly illustrated in cases when clinicians ask surrogates to make decisions about life-saving measures that reflect the patient's desires. In some cases, surrogates who did not have explicit discussions about such matters with their loved ones had to speculate about what the patient might want. Although it is not particularly surprising that many patients had not disclosed their desires for palliative care and life-saving measures to their families given the complex nature of such conversations (Hines, 2001), our study highlights the toll that this lack of information can take on surrogates. Not knowing the patient's wishes in the face of clinicians who are expecting, and sometimes demanding, such information from the surrogate can cause great distress. On the other hand, surrogates in this sample who knew what the patient wanted found that this aided in the decision making processes. For example, although decisions about end-of-life care were fraught with emotion, surrogates who had discussed these possibilities with the patient relied on this information when making difficult decisions and had an easier time making the decision.

### **Practical Implications**

The insights from surrogate decisions makers in our sample offer a number of potential practical implications. As the aging population continues to grow, it is likely that health care providers will encounter more and more surrogate decisions makers. As such, health care providers, the organizations that employ them, and surrogate decision makers would all benefit

from educational seminars and materials designed to improve surrogate-clinician interactions. For instance, the inconsistent sharing of information within the same hospital described in this study suggests that clinicians would benefit from ongoing training about best practices. In addition, those who are serving in the surrogate role would benefit from education about hospital practices and the challenges they might encounter in fulfilling their responsibilities as surrogates. Understanding that they may encounter resistance from clinicians, will need to interact with multiple clinicians, and might face stumbling blocks to accessing information, may help surrogates be more aware of these issues so that they can know what to expect.

Our findings also highlight the important role that advance care planning conversations have in preparing the surrogate to make difficult decisions. Advance care planning is the process of considering one's health care wishes for a future time when he or she may no longer be able to participate in medical decision making. While such conversations ideally lead to completion of written advance directives, there is growing awareness of the need to include the surrogate in those conversations so that the surrogate will be knowledgeable about the patient's preferences and able to fully participate at the time of decision making (Sudore & Fried, 2010). In the present study, surrogates who were knowledgeable about the patient's wishes and were able to convey them to clinicians described experiencing less anxiety. Our findings are consistent with other work that found not knowing patient preferences is a source of anxiety in surrogate decision making (Wendler & Rid, 2011).

### **Limitations and Opportunities for Future Research**

Like most studies that rely on accounts of interactions, our ability to make claims about the nature of surrogate-clinician encounters is limited by our reliance on surrogates' recollections of their communication with health care providers. However, there are two ways in which to

frame the viability of these data. First, we sought to maximize participants' ability to recall specific conversations by conducting interviews as soon as reasonably possible after decisions were made. Second, as the research on memorable messages suggests, we found that participants tended to be able to describe memorable interactions in detail based on the salience of the situation (e.g., Knapp, Stohl, & Reardon, 1981; Smith, Nazione, & LaPlante, 2009).

Our study is also limited in scope because our interviews include only the perspectives of surrogate decision makers and not the perspectives of the clinicians with whom they interacted or other family members who might have taken part in decision-making processes. Future research could expand our understanding of the privacy management challenges identified in this study by talking to clinicians to gain their insights on conversations with surrogates. Although our data point to some of the potential challenges that health care providers face in getting information from surrogates, such as surrogates' lack of knowledge about patients' wishes, it is possible that clinicians encounter a number of other dilemmas not apparent in the current data. For example, health care providers might be uncertain about how to enforce regulations like HIPAA or might face dilemmas when they disagree with stipulations that prevent them from sharing information with families (Stone, 2013).

Finally, future research and theorizing should focus on enlarging models of patient-provider interaction. Torke and colleagues (2012b) noted that most models of patient-provider communication and surrogate-clinician communication assume a dyadic relationship that is not "well suited to the modern hospital environment" (p. 5). The current analysis reiterates this point. Our findings suggest that surrogates interact with a team of physicians, nurses, and allied health professionals and that the range and variety of medical encounters that surrogates must manage are not well-explained by dyadic models.

### **Conclusion**

As the U.S. population continues to age, and rates of communication-debilitating illnesses and injuries (Bute et al., 2007) continue to grow, surrogate decisions makers will become increasingly common in both hospital settings. Clinicians and families must prepare to meet the challenges that accompany performing the surrogate role and the associated responsibility of proxy ownership. Identifying the privacy management challenges faced by surrogates, as outlined in this study, is one step toward reducing the stress that accompanies the surrogate role and improving health outcomes for patients.

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Table 1. Participant Characteristics (N=35)

<b>Characteristic</b>	<b>Number of Surrogates</b>	<b>Percent (%)</b>
<b>Race:</b>		
African American	18	51.4
White	17	48.6
<b>Gender:</b>		
Female	28	80.0
<b>Education:</b>		
9-12 years	20	57.1
13-16 years	11	31.4
17+ years	4	11.4
<b>Religion:</b>		
Protestant	29	82.9
Catholic	3	8.6
Spiritual	1	2.9
None	2	5.7
<b>Patient Location at time of</b>		
<b>Died in the Hospital</b>		
<b>Relationship of Surrogate to</b>		
Daughter	21	60.0
Son	5	14.3
Sister	2	5.7
Spouse	2	5.7
Nephew	1	2.9
Niece	1	2.9
Grandson	1	2.9
Other	2	5.7

Table 2. Number of decisions and patient location at the time decision was considered.

Decision	Location of Patient at Time of Decision		
	ICU (13 patients)*	Ward (22 patients)*	Total (35 patients)*
Life sustaining Therapy	5 (38.5%)	19 (86.4%)	24 (68.6%)
Procedures/surgery	12 (92.3%)	16 (72.7%)	28 (80.0%)
Nursing Home Placement	2 (15.4%)	12 (54.5%)	14 (40.0%)
Total Decisions			66

\*Percents reflect the number of patients who faced the decision (numerator) over the number in that location (denominator). Many patients faced more than 1 decision, so column totals exceed the number of patients in that location.