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## Communicating with Clinicians: The Experiences of Surrogate Decision Makers for Hospitalized Older Adults

Alexia M. Torke, MD, MS<sup>a,b,c</sup>, Sandra Petronio, PhD<sup>b,d</sup>, Christianna E. Purnell, BA<sup>a</sup>, Greg A. Sachs, MD<sup>a,c</sup>, Paul R. Helft, MD<sup>b,e</sup>, and Christopher M. Callahan, MD<sup>a,c</sup>

<sup>a</sup> Indiana University Center for Aging Research, Regenstrief Institute, Inc., Indianapolis, IN

<sup>b</sup> Charles Warren Fairbanks Center for Medical Ethics, IU Health, Indianapolis, IN

<sup>c</sup> Division of General Internal Medicine and Geriatrics, Indiana University School of Medicine, Indianapolis, IN

<sup>d</sup> IUPUI Department of Communication Studies, Indianapolis, IN

<sup>e</sup> Indiana University Melvin and Bren Simon Cancer Center, Indianapolis, IN

### Abstract

**Background/Objectives**—When hospitalized older adults have impaired cognition, family members or other surrogates must communicate with clinicians to provide information and make medical decisions for the patient. The present study describes communication experiences of surrogates who recently made a major medical decision for a hospitalized older adult.

**Design**—Semi-structured interviews about a recent hospitalization.

**Setting**—Two hospitals both affiliated with 1 large medical school: an urban, public hospital; and a university-affiliated tertiary referral hospital.

**Participants**—Surrogates were eligible if they had recently made a major medical decision for a hospitalized patient aged 65 or older and were available for an interview within 1 month (2–5 months if the patient died).

**Measurements**—Interviews were audio-recorded, transcribed, and analyzed using methods of grounded theory.

**Results**—We interviewed 35 surrogates. They were 80% female, 44% white and 56% African American. Three primary themes emerged. We found the *Nature of Surrogate/Clinician Relationships* was best characterized as a relationship with a “team” of clinicians rather than individual clinicians due to frequent staff changes and multiple clinicians. Surrogates reported their *Communication Needs*, including frequent communication, information, and emotional support. Surrogates valued communication from any member of the clinical team, including

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Corresponding Author: Alexia Torke, MD, MS IU Center for Aging Research 410 W. 10<sup>th</sup> St. Indianapolis, IN 46202 317-503-8084  
Fax 317-423-5695 atorke@iupui.edu Alternate Corresponding Author: ccallaha@iupui.edu.

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nurses, social workers, and physicians. Third, surrogates described *Trust and Mistrust*, which were formed largely through surrogates' communication experiences.

**Conclusion**—In the hospital, surrogates form relationships with a “team” of clinicians rather than with individuals. Yet effective communication and expressions of emotional support frequently occur and are highly valued by surrogates. Future interventions should focus on meeting surrogates' needs for frequent communication, high levels of information and emotional support.

### Keywords

Communication; Proxy; Physician-patient relations

## INTRODUCTION

Up to 40% of hospitalized adults have impaired cognition and require the assistance of a family member or other surrogate to make medical decisions,<sup>1</sup> a number likely to be even higher for older adults due to the higher rate of dementia, delirium and other forms of cognitive impairment. Having a surrogate may increase the complexity of communication and decision making<sup>2-4</sup> and may, in some cases, mean that key decisions such as code status are delayed by as much as a day.<sup>5</sup>

Prior research has shown that family members of seriously ill hospitalized patients often report poor quality communication<sup>6</sup> but that certain communication strategies improve surrogate satisfaction, including increased time for the family to speak in family conferences,<sup>7</sup> increased expressions of empathy<sup>8</sup> and consistent communication by health care team members.<sup>9</sup> One study found that early family meetings for dying patients can reduce surrogate post traumatic stress symptoms for surrogates.<sup>10</sup>

Although qualitative studies have examined the decision making experiences of the surrogate,<sup>11-23</sup> only a few have focused specifically on surrogate/clinician communication. These have identified important communication needs in the ICU<sup>14, 18, 21</sup> and among surrogates of Veterans from a variety of clinical settings,<sup>16</sup> including the need for clinician availability and continuity, the need for clinicians to clarify family roles and foster consensus, timely communication, frank information, recommendations, and respect. These studies have been conducted 2 months to 22 months after decision making<sup>14, 18, 21</sup> or have involved persons who had been surrogate decision makers at any time in the past.<sup>16</sup>

Although seriously ill hospitalized older adults are likely to require surrogate decision makers and to face complex decisions, we are unaware of prior studies that have focused on the communication experiences of their surrogates. The goal of the present study was to describe the communication experiences of surrogates making decisions for hospitalized older adults. To achieve this goal, we conducted semi-structured interviews with surrogate decision makers during or soon after they made a major medical decision for a hospitalized older adult, in order to capture surrogates' communication experiences as close to the actual decisions as possible.

## METHODS

### Study Design and Population

Interviews were conducted at 2 hospitals both affiliated with 1 large medical school (an urban, public hospital and a university-affiliated tertiary care referral hospital) as part of a larger observational study of the process and outcomes of surrogate decision making. The

public hospital is staffed by teams that include an attending physician (hospitalist or general internist), a resident, 2 interns and 2-4 medical students. ICU teams are staffed by a critical care attending and fellow, a resident and 2 interns. The tertiary hospital is staffed by teams that include a hospitalist and a resident or nurse practitioner and in the ICU by a critical care attending, fellow and often a resident. Most physicians rotate monthly or biweekly. Nurses in both hospitals receive patient assignments daily. ICU nurses often attend bedside rounds but medical ward nurses do not. Patients 65 and older admitted to the medicine and medical intensive care unit (ICU) services of the hospitals were identified within 48 hours of admission using the electronic medical record. During the admission, a research assistant briefly spoke 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 those involving: life sustaining care (e.g., code status, ventilation, 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. Surrogates who were family or friends were contacted by phone or at the bedside. Surrogates who were public guardians were not included in the study. The Indiana University Institutional Review Board approved the study. We obtained a waiver of consent for recruitment that allowed us to identify eligible patients through the electronic medical record and to determine if the patient had a surrogate decision maker. Prior to the interview, written informed consent was obtained from each surrogate.

Interviews were initially conducted with surrogates from both the medical wards and 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, we focused subsequent interviews on participants in this setting, a qualitative research strategy called purposive sampling.<sup>24</sup>

### Data Collection

Interviews were conducted by one of two investigators (AMT or CP) in a hospital conference room or the surrogate's home. 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 between 2-5 months after patient death, a time interval similar to those in other after-death family interviews.<sup>25</sup>

The semi-structured interview guide was based on a conceptual model of surrogate decision making developed by the authors.<sup>4</sup> The model proposes that there are two major elements of surrogate/clinician communication, information processing and relationship building. These elements of communication are associated with the quality of medical decisions and these, in turn, affect outcomes for both patients and surrogates. Major questions in the interview guide corresponded to the constructs in the model (see Appendix). The interview guide contained major questions, followed by a series of optional prompts to further explore the topics. The recruitment method and interview guide were pilot tested with 7 surrogate decision makers and refined prior to the start of the study.

### Data Analysis

Interviews were audio-recorded, transcribed verbatim, and analyzed using grounded theory, a well-established approach to analyzing qualitative data.<sup>26-27</sup> The data analysis involved coding, a process in which investigators identified and labeled segments of text by topic. Researchers met regularly throughout the analysis to discuss codes and identify broader

themes that emerged from the interviews. Codes and themes were entered into NVivo (QSR International, Cambridge, MA) to allow for the organization of coded interview data.

The first ten interviews were read and independently coded by three investigators (AMT, SP, CP). Subsequent interviews were coded by one investigator and code-checked by all three. These investigators met after every 3 to 5 interviews to discuss emerging themes. Differences of opinion were resolved by consensus. Coding and team meetings were conducted concurrently with further data collection. At each meeting, coders assessed whether enough data had been collected to reach “theme saturation,” or the point at which additional interviews do not yield new codes or themes. For the present study, we examined all codes related to communication between clinicians and surrogates.

Qualitative research methods involve several steps to ensure credibility, similar to validity in quantitative studies.<sup>28</sup> Investigators took the following steps to ensure credibility: more than one investigator conducting interviews; analysis by an interdisciplinary team including a general internist physician and an expert in communication theory; and an interview process that continued until theme saturation was reached.

## RESULTS

We conducted 835 physician interviews and identified 595 patients where at least one major decision was made. 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 completed semi-structured interviews with 35 out of 100 using the method described above (Table 1). Thirteen interviews were conducted regarding decisions in the ICU. Seven of these were collected after making the decision to focus interviews on the ICU setting. The mean duration of interviews was 40 minutes (range 13-85) and yielded 796 double-spaced pages of transcribed text. Mean time from 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 (Table 2).

### The Nature of Surrogate/Clinician Relationships

**Relationship with a Team**—Surrogates rarely formed personal relationships with individual hospital clinicians who were important in the patient’s care. Instead, surrogates perceived that they had a relationship with “the hospital” or with “the team.” For example, when asked if there was anyone she could rely on, one surrogate answered, “The nurses’ station.” (O11) Another described satisfaction with the phone calls she had received from multiple members of the clinical team, yet, did not identify any individual medical staff member with whom she had established a relationship:

But, one thing I will say is that the staff here, with their having, ... I believe three different teams for mom, they were in contact with me on almost [on] a daily basis, which I had never really been used to that in any of the hospital stays, which have been hundreds over the years, that the hospital had kept in contact with me as much as they did. I was extremely impressed that I had gotten so many calls from a team member from W Hospital.

One surrogate went so far as to characterize his interactions as being something other than a relationship:

Well, they [medical team] seem to be pretty caring. I mean, there’s not a relationship but they do try to explain everything and offer me to ask some questions if I don’t understand.

Two major contributors to the surrogates' perceptions of an inability to establish personal relationships were frequent changes in the clinicians caring for the patient and the large number of clinicians involved in the patient's care. One surrogate described the difficulty in determining who her mother's physician was due to the multiple clinicians involved and therefore the frustration in knowing who turn to for information:

One lady came in and she said that she was a doctor, and [said] that this was her last day, but she was over Mom and [what] the new doctor was doing to take over tomorrow. I was trying to figure that one out... So, who is the doctor? You know, one specific person you could say, hey, look, I need an answer.

In general, surrogates relied on multiple members of the clinical staff, including physicians, nurses, and social workers. Many surrogates seem to place similar, if not equal, importance on communication from various members of the clinical team.

**Role-Based Relationships**—While surrogates were typically unable to name the individual medical team members, we did find that they could name the hospital role of the clinicians involved in care. As one stated:

Well this one nurse. I don't know her name, but she calls me every time...I never even met her, but over the phone. But that's about the closest relationship I got.

Our findings also revealed that surrogates were mindful they did not know the medical team member's names and seemed to express embarrassment about this. They frequently commented on or apologized for being unable to name any clinician directly involved in the patient's care. Nevertheless, they did know their role.

The doctors came in and reviewed...her history, et cetera...I'm sorry I don't remember the two doctors' names, but they were actually part of the respiratory care area.

### Communication needs

Despite the limited opportunity to form ongoing relationships with clinicians, surrogates were able to express their needs and expectations for communication, providing positive and negative examples of meeting these needs. The three major communication needs we identified were *Frequent Communication*, *Information*, and *Emotional Support*.

**Frequent Communication**—The frequency of communication interactions was a key element of surrogates' hospital experience. One described his appreciation for daily updates about the patient:

It made it less stressful for me because I can keep abreast of what was going on.

The frequent contact served to reduce anxiety and increase trust that the patient was receiving good care. Conversely, surrogates mentioned trouble contacting the physician or other clinicians as a communication problem that left them feeling frustrated.

**Information**—In some cases, surrogates struggled to gain important information about what was going on with their family member. One son described:

.....information that was kind of shared haphazardly...mainly by the nurses who were saying that there was some discussion about some kind of procedure. Well, trying to find out, number one, had the procedure been done, and if it had been done, what did it show and then what was going to happen as a result of the procedure.

A particularly important communication problem was the use of jargon or technical language to convey what seems to be salient information about the patient, leading to poor understanding and confusion on the part of the surrogates.

I think particularly young doctors are more prone to use jargon, and if you don't stop them and say, excuse me, I don't understand what you're talking about...you lose that.

Surrogates' examples of receiving information suggest that information played multiple roles in their hospital experience. In some cases the information was important for decision making, but it also played other key roles, such as demonstrating caring.

... taking the time out to really sit there with me to explain that to me, that meant a lot to me cause some doctors they will tell you and explain it to you and then they move on. But she actually, I felt like she really cared about what was really going on with my mom...So you know everybody was letting me know everything which made me feel a little bit more comfortable.

**Emotional Support**—As demonstrated above, there was a close relationship between information giving and emotional support. When clinicians took time to provide information or contact the surrogate frequently, the surrogate appeared to feel supported. One family member gave her overall assessment of the hospital:

I've never had any negative experiences here and I've never had people that seem like they just didn't care about either the patients or the family members and they were willing to answer questions, or they were willing to be there for you and comfort you in any way they can or direct someone there to help you, or you now...I feel like they truly care.

Expressions of empathy, in which clinicians reflected understanding of the surrogate's experience, were also valued.

He was very caring...He kind of said, I understand you want to get your mom through this. He kind of gave us the pros and cons.

### Trust and mistrust

Trust and mistrust were often demonstrated through stories rather than explicitly described. These stories illustrate both the levels of trust or mistrust felt by the surrogates and the different domains in which trust is experienced, including trust that the surrogate will be kept informed, trust that the hospital has the patient's best interest in mind, or trust that the patient will receive quality care. One surrogate described why she requested the patient be taken to the study hospital:

I would rather for her to go to W because I like the way the doctor team calls me and lets me know what's going on. 'Cause I work nights and I can't be there all the time.

This surrogate's feeling of trust was based on her expectation that she would be kept informed about the patient's status. Through their stories, surrogates revealed their interpretations of clinician behavior that contribute to trust or mistrust. For example, one surrogate recounted his belief that his mother's pain was not adequately treated because of her Medicaid status:

They have the pain medicine here. It's just a shame that they reluctant to give it to her because they didn't think they were gonna get their money for it, so she had to lay here and suffer the whole time.

Surrogates also developed trust by comparing their own observations to what they were told:

You know, I seen what they was telling me, that it was accurate. Everything was getting better and I was glad of that.

It was rare that surrogates explicitly mentioned trust as a factor in their experience.

These interviews showed a complex relationship between information and trust. Taking the time to meet the surrogate's needs for information, frequent communication and support built trust. In turn, this trust led to greater receptiveness to information from clinicians.

## DISCUSSION

Our interviews with surrogate decision makers for hospitalized older adults revealed that relationships with clinicians are often fragmented and brief. Surrogates defined those relationships more generally in terms of "the team" of clinicians rather than with specific clinicians. In spite of this, expressions of support and exchanges of information frequently occurred between surrogates and the clinical team and were highly valued.

Prior conceptual work describing the patient/physician relationship<sup>29-30</sup> and the surrogate/physician relationship<sup>2-3</sup> frame these relationships as necessarily dyadic, between a single patient or surrogate and a single clinician. This model does not appear well suited to the modern hospital environment, where staff changes occur frequently and there is little time to form personal relationships. Instead, we found hospital-based interactions are based more on a professional role, as a doctor, nurse or social worker than on relationships with particular individual caregiver. Many individuals may serve in each role over the course of a patient's hospitalization. The brevity of these relationships is likely to be exacerbated by several forces, such as the presence of hospitalist physicians who also work in shifts and are unlikely to have had a relationship with the patient or family prior to admission.<sup>31</sup>

Surrogates often apologized for their failure to remember clinicians' names, even those with whom they had an especially positive or meaningful interaction. Arora et al found that this is common, with 75% of hospitalized patients unable to name a single physician who cared for them.<sup>32</sup> Surrogates' apologies suggested this failure to remember names violated their own expectations. However, in many cases the surrogates appeared to be generally satisfied if the communication was deemed meaningful. It may be that while surrogates' expectations for continuity are violated, their overall level of satisfaction depends more on whether their communication needs are met. These needs can be successfully addressed by multiple clinicians who fulfill their role in the patient's care. For example, a surrogate may have an extremely positive interaction with a nurse who provides information and support, therefore inspiring trust, but who never cares for the patient after her current shift. In such cases the surrogates may remember important elements of the interaction but not the nurse's name.

Throughout the interviews, surrogates were able to characterize the elements of communication that were salient to them. These included frequent contact, high degrees of information about the patient, and emotional support. A prior survey of physicians has found that communication with surrogates is often delayed or infrequent.<sup>33</sup> The present study as well as other research with surrogates in other settings<sup>16,18</sup> suggest that such delays may be a cause of distress for surrogates.

Although information was important for decision making, surrogates describe other roles that information played in their experience. For example, information sharing was perceived as emotionally supportive. Likewise, comparing what clinicians told the surrogate to the surrogate's own observations built trust. These findings suggest a complex relationship between information sharing and relationship building. Other authors have noted the

multiple roles that information plays for patients, such as emotionally preparing the person for the future.<sup>34</sup> Our interviews suggest that information plays similar roles for surrogates.

A recent review emphasized the extent to which surrogate decision making is a source of substantial distress to the surrogate, leading to clinically significant PTSD symptoms in some cases.<sup>35</sup> That stress is likely to stem from many sources, including facing the severe illness of a loved one and serving as a decision maker.<sup>36</sup> Our study identifies ways in which clinician/surrogate communication has the potential to exacerbate or alleviate distress. We found that surrogates find comfort in frequent communication and high information disclosure about pertinent issues for the patient. They find it stressful when they struggle to obtain information and value explanations that are clear and jargon free. Future research is needed to explore whether better meeting these specific communication needs could decrease surrogate distress.

Our findings about the nature of surrogate/clinician relationships also raise the question of whether greater continuity would be preferred to the current, highly fragmented model of care. The high number of clinicians involved and fragmentation of care may pose a substantial burden for surrogates.<sup>16</sup> One solution would be to return to models of care that provide greater continuity of providers. This change in hospital care seems unlikely in the near future. Alternatively, it is possible to focus on improving communication with surrogates within the current framework, by increasing the elements of communication we have identified as most important. Thus, looking at surrogates' communication needs for frequent contact, information, and emotional support can be used to develop new approaches for the hospital care of patients with cognitive impairment.

This study has several limitations. Interviews took place in a single metropolitan area at two teaching hospitals. As such, it did not include patients cared for in rural health settings or in community hospitals without trainees, two settings where clinician/patient relationships may have greater continuity or may differ in other ways. Our study relied on interviews with surrogates and did not directly observe communication. We interviewed a single surrogate for each patient, when in some cases physicians may have also needed to communicate with multiple surrogates. Future work could examine communication challenges that may occur when there are multiple surrogates. Patients in the present study were almost all white or African American, and our findings may not reflect the perspectives of other ethnic groups such as Asians or Latinos. The qualitative approach allowed us to identify important themes in communication; the next step in this line of research will be to develop quantitative measures and to test hypotheses related to the impact of communication has on surrogates' experiences and outcomes.

In conclusion, relationships between surrogates and clinicians are fragmented and brief. Rather than forming relationships with individuals, the surrogate experiences a relationship with a "team." In spite of this, many surrogates were satisfied when clinicians met their communication needs. Frequent contact, information, and emotional support should be standard in providing care to patients with cognitive impairment. The fact that surrogates are open to receiving information and support from multiple types of clinicians points to an interdisciplinary approach for improving the quality of surrogate/clinician communication.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.



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**Table 1**

## Participant Characteristics (N=35)

Characteristic	Number of Surrogates	Percent (%)
<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 Decisions</b>		
Medical Ward	22	62.9
Intensive Care	13	37.1
<b>Died in the Hospital (prior to interview)</b>		
	4	11.4
<b>Relationship of Surrogate to Patient:</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.

Elements of Financial/Personal Conflicts	* Author 1 Torke		Author 2 Petronio		Author 3 Purnell		Author 4 Sachs		Author 5 Helft		Author 6 Callahan	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Employment or Affiliation		X		X		X		X		X		X
Grants/Funds	X			X		X		X		X		X
Honoraria		X		X		X		X		X		X
Speaker Forum		X		X		X		X		X		X
Consultant	X			X		X		X		X		X
Stocks		X		X		X		X		X		X
Royalties		X		X		X		X		X		X
Expert Testimony		X		X		X		X		X		X
Board Member		X		X		X		X		X		X
Patents		X		X		X		X		X		X
Personal Relationship		X		X		X		X		X		X

\* Authors can be listed by abbreviations of their names

**For “yes”, provide a brief explanation:** ... Dr. Torke was supported by a Geriatrics Health Outcomes Research Scholars Award sponsored by the American Geriatrics Society and the John A. Hartford Foundation and a career development award from the National Institute on Aging (K23AG031323). She is also a consultant on a Retirement Research Foundation grant to the Wishard Volunteer Advocates Program, a public guardianship program for adults. Dr. Callahan is supported by a Midcareer Investigator Award in Patient Oriented Research (K24 4682309). These funders had no role in the design, methods, subject recruitment, data collections, analysis, or preparation of paper.

Dr. Sachs serves as a consultant to the National Pharmacy and Therapeutics Committee of CVS Caremark and he receives an honorarium for this role. Dr. Sachs is one of two individuals on the committee who were selected because of their specific geriatrics credentials and experience. If Dr. Sachs attends all four of the quarterly meetings, plus additional brief phone consultations, his annual compensation for these activities may total in the \$12,000 to \$15,000 range.

In this role for CVS Caremark, Dr. Sachs is asked to comment on and advise with respect to the safety and efficacy of medications as they are reviewed for inclusion on various formularies, preferred prescribing guides, and clinical programs. Attention is given to ensuring that patients’

health would not be put at risk by any formulary decisions. There is a strict “firewall” between this review process and business considerations of CVS Caremark such as prices, cost effectiveness, and contracts with clients or pharmaceutical firms (i.e., Dr. Sachs and other committee members are not privy to any of this other information).

Dr. Sachs’s own research program relates to ethical issues encountered in clinical care and research involving people with dementia, including end-of-life care issues. Dr. Sachs does not conduct medication trials and has no relationships with pharmaceutical or equipment companies.