Dawning of Awareness: The Experience of Surrogate Decision Making at the End of Life

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While out for an evening with friends, Sarah received a call; her mother had collapsed and had been rushed to the hospital. Her mother was in a coma when Sarah arrived at the hospital and remained so until the moment of her death a week later. Full life support was provided in the intensive care unit (ICU) over the next week, while physicians and nurses waited with Sarah to see if there would be any improvement, any sign of life. At the end of the week, the team sat down with her and suggested that all treatment be stopped. Many times in the past her mother had told her, "If there is no hope, let go," so Sarah agreed with the team. Sarah was 22 years old. She had never felt so alone.

The literature on surrogate decision making is expansive. The substituted-decision standard[1] and the best-interest standard[2] outline two specific methods to guide decisions on behalf of individuals who are no longer competent to make decisions for themselves. Lack of congruency in decision making between surrogates and patients and surrogates and healthcare professionals has been explored extensively.[3] There has been an ongoing examination of the role of the family members as surrogates,[4] and the courts have intervened to resolve conflicts that arise when professionals and surrogates cannot agree.[5]

Despite this, the clinical reality of a 22-year-old woman who finds herself alone, afraid, and in a position in which she must make end-of-life decisions for her 47-year-old mother in an ICU often seems quite removed from the world presented in academic journals. The current ethical and legal literature suggests that a shared decision-making approach is preferred;[6] however, physicians and nurses struggle to involve surrogates in end-of-life decision making while they attempt to prevent the invariably difficult role from becoming a burden. Surrogates, each from a unique background and experience, expect to have a role in making decisions, but are often overwhelmed by the environment, the information being shared, and the actual responsibilities for which they feel completely unprepared. The ever-present emotional and spiritual angst that accompanies the anticipation of death is often sandwiched between the technological push to save lives and the struggle of surrogates to try to understand what is happening, as well as how it should be interpreted.

There has been little examination of the actual experience of surrogates as they make decisions. Having an understanding of the cognitive and emotional processes of surrogates will assist physicians, nurses, ethicists, and other professionals to tailor professional interventions to assist surrogates in fulfilling their roles.

To this end, we interviewed surrogates who were involved in making end-of-life decisions for a family member in an ICU, to learn about the experience of making decisions to stop treatment. These surrogates also participated in analysis of the data collected in our study, so that the reflections on what had been discussed would be as rich as possible. These results were analyzed and expanded through comparison with the literature and have been oriented to the clinical setting, to provide clinicians with some foundations to use in enhancing shared decision making at the end of life.

REVIEW OF THE LITERATURE

DECISION-MAKING STANDARDS

It is clear in law and in practice that a competent adult has the right to both make and be involved in decisions to consent to or refuse care. Laws in most jurisdictions provide a method for an adult who becomes incompetent to be represented by a surrogate who can reflect the patient's values and beliefs and make decisions on the patient's behalf, or by a court if a surrogate does not exist.

Two ethical decision-making standards have evolved: the substituted-judgment standard and the best-interest standard. Substituted judgment requires that surrogates "reach that decision which the incompetent patient would have chosen had he or she been competent."[7] This presumes that the substitute decision maker is able to preserve the patient's self-determination by thinking and deciding as the patient would have. The literature suggests that evidence should be categorized in terms of its proximity to the actual decisions the competent patient would make (for example, the primary source would be an advance directive). If the surrogate has little or no relevant knowledge, then decisions will need to be guided by the best-interest standard.[8] There is controversy, however, on whether the preservation of patients' autonomy is possible through a third party, and it has been suggested that different principles apply when making decisions for oneself than when doing so for another.[9] The prevailing belief, however, continues to be that the use of a surrogate decision maker seeks to extend the autonomy of the capable patient into a time when the patient is no longer capable.

In the absence of knowledge about a patient's values and beliefs, the best-interest standard endeavors to ascertain the most important interests of the patient. The decision maker attempts to determine "the medical course of action most likely to maximally contribute to the patient's welfare."[10]

CONGRUENCY OF PATIENTS' PREFERENCES WITH
THOSE OF SURROGATES AND PROFESSIONALS

Recent research in the field of patients' preferences reports that most patients want end-of-life decisions to be made by family members, and that, in making decisions on their behalf, families consider their quality of life, cognition, competence, seriousness of illness, and subsequent hope of recovery.[11] While most studies report that patients trust that family members will make appropriate choices on their behalf, recent studies indicate that there is little congruence between patients and their family members on such decisions.[12] Despite these findings, a recent study has reported that if a conflict arises between what has been stated on a prior basis by the patient and what the surrogate believes to be the best decision, patients preferred that their surrogate's decisions take priority over their previously stated wishes.[13]

WHAT ROLE SHOULD THE SURROGATE HAVE IN DECISION MAKING?

Three authors have outlined the debate about how patients' families should be involved as surrogates. Hardwig, in a controversial approach, suggests that the interests of family members and patients should be respected equally in any decision-making process, and argues that individuals cannot be separated from their interconnected lives in the family.[14] Nelson tempers this discussion by suggesting that, while the patient's

decisions could not be totally void of any reflection on their impact on families, a more equitable approach might be to work toward a consensus that would suit all family members.[15] Blustein suggests a re-orientation of the family role that would mimic a more communitarian concept of family, in which members are interrelated and interdependent, and in which family members act as mentors and facilitators while they provide support to the patient.[16] It is unclear that any of these approaches would be clinically viable; for example, family members may not want to accept that their needs are of equal importance to those of the patient. When one member of a family is ill, the other members usually cede their own interests, especially in end-of-life situations, and often refuse to pay attention to even the most significant of their own needs. While consensus-building is the ideal, it is not always possible, due to such factors as multiple perspectives, geographical distance, and family conflict. Finally, while family members typically strive to provide support, fulfilling the role of a surrogate decision maker may be impossible when a surrogate does not accept the role or does not feel capable of fulfilling it.

Further, in an increasingly secular world, it is often difficult for family members to have their religious convictions understood or respected. For family members who are trying to balance convictions that are integral both to their family and to their faith, a conflict with healthcare professionals that arises from a misunderstanding or a clash with current thinking in medicine will only increase the burden and frustration of the family's surrogate experience.[17]

Families can be frustrated by what they may see as a distressing lack of certainty in "prognostication" on the part of professionals.[18] Uncertainty about diagnosis and prognosis can create an environment in which families feel that discussions contain only an illusion of truth, and that pertinent information remains hidden. The aura of mistrust that can sometimes accompany these difficult discussions may play a major role in the ongoing struggle to find an appropriate patient-professional partnership for making decisions.[19]

SHARED DECISION MAKING

Patient-professional relationships have shifted along a spectrum in the last two decades, from "medical paternalism" toward "patient sovereignty."[20] At the far end of paternalism, physicians are dominant, authoritarian figures who have the right and responsibility to make decisions regarding the medical best interest of patients. At the far end of sovereignty, patients have full responsibility and control over all decisions concerning their own care, and while practitioners share information and knowledge, they do not exert influence on the decisions made by patients.[21]

Neither of these approaches reflects the interactions that are necessary to plan and execute reasonable, respectful care in the real world. Current practice and ethical analysis lean toward what may be perceived as a shared approach, in which clinicians and family members work together to build consensus.[22] These approaches recommend (1) sharing information between professionals and surrogates, (2) developing a team approach,[23] (3) interpreting treatment options for family members, and (4) understanding the patient's context.[24]

The large and oft-quoted SUPPORT Study attempted to improve end-of-life decision making, but failed to gain many of its expected outcomes.[25] While the types of information shared increased and additional team members became involved to assist in the translation of information, the study measured little change in the actual approaches of the physicians in the study.[26] One qualitative study explored the experiences of family members who were asked to withdraw treatment, and found that surrogate decision makers need to understand not only the current medical situation of the patient, but need an opportunity to review the life of the patient and the role of the surrogate in relation to the patient and family members to be able to withdraw treatment.[27]

To further expand knowledge of surrogates who make decisions at the end of life, we undertook a phenomenological study. We sought to further explore the cognitive and emotional processes and the lived experiences of surrogates who must make very difficult decisions to withdraw treatment. An enhanced understanding of these cognitive and emotional processes will help us to tailor and sensitize clinicians' ap-

proaches to end-of-life discussions. We found that a shared decision-making process, while most desirable, requires careful attention to the presentation of information and the support and preservation of the roles and relationships of surrogates.

METHODS

Approval for the study was received from the McGill University Health Center research ethics board.

THEORETICAL FRAMEWORK

We chose an interpretive approach as the theoretical framework for the empirical component of this study. Also called *interpretive phenomenology* or *hermeneutics,* this qualitative methodology is based on a conception of human agency in which moral life is rooted in the context in which it is lived.[28] An interpretive approach seeks to understand human experience through thick contextual description.[29] It is based on a notion that understanding in human experience inescapably involves interpretation. An encounter or an experience is interpreted in terms of acquired understandings or a search for meaning. An experience of a particular encounter will reshape a person's "interpretive framework," the system of understandings that are brought to subsequent encounters, so that she or he will approach other encounters with a new or different interpretation.[30]

STUDY DESIGN

The phenomenon we explored was the primary surrogate decision maker who makes end-of-life decisions in an ICU. The principal investigator (or PI—the first author) conducted face-to-face interviews with the participants in the study: two broad-fact-finding participants (BFs) and six primary surrogate decision makers (PSs). The data were analyzed and interpreted throughout the data collection process and included the participants. The steps followed in the collection, analysis, and interpretation are integral to the design of the study, and are outlined in table 1.

In the interpretive approach, it is an asset for the PI to have an understanding of the experience or situation that is being explored. In this study, the PI had worked in the ICU setting for 15 years; 13 as a clinical nurse specialist with the specific role of patient and family counselor. Her knowledge of the ICU environment and of the experience of patients and families who face critical illness and death was useful in developing probing questions that would gain rich experiential data from the participants, in conducting sensitive interviews with participants who were still mourning their loss, and in the interpretation of the transcripts of the interviews.

SETTING

An ICU of a tertiary level academic teaching hospital was the setting in which the PSs were identified and recruited. All interviews were conducted at the participants' homes or the in the PI's office, according to the preference of the participants.

PARTICIPANTS

The goal of interpretive phenomenology is to gain a richer understanding of the phenomenon being studied, so we chose participants specifically for their ability to share and articulate their experiences. The BFs were identified by the PI following consultation with colleagues; she made an effort to identify people with extensive, relevant experience. Both of the BFs were volunteers in different areas of the hospital, and had acted as surrogates in their own families; they were able to describe the reactions, emotions, and problems they faced, and their interactions with staff. They were also able to talk about their discussions with family members of other hospital patients about the world of the patient and family in terminal illness.

The BFs were approached individually by a colleague of the PI and asked if they were interested in meeting the PI to discuss the possibility of participating in the research. Both agreed, met with the PI, who

explained the interview and analysis process and responded to their questions. The BFs gave their verbal and written consent to participate in the study. All of the PSs were identified and approached by the nurse manager of the ICU after a detailed discussion of the goals and design of the study with the PI. All of the PSs had acted as the primary surrogate decision maker on behalf of a patient who had died in the ICU approximately six months prior to the study; had an ability to speak in either English or French; and had indicated a willingness to discuss their experience. The PI chose the PSs to include different ages, genders, and relationships with patients. The PI met with potential PSs to discuss the research, explain the interview and analysis process, and respond to questions. PSs who participated in the study gave verbal and written consent.

Due to the time and financial constraints of a one-year research fellowship and the need for two interviews per participant (and potentially more, depending on the interpretive process), the study was limited to eight participants.

DATA COLLECTION AND ANALYSIS

Phenomenology seeks a deeper understanding of an experience or phenomenon. Other methodologies usually delineate between the collection and analysis of data, but phenomenology requires a blending of, or a cyclical or interactive approach to seeking and interpreting data in the form of rich text and discussion, which helps to provide a confirmed narrative. To enrich the knowledge of the PI and to avoid a potential misinterpretation of the experience of patients and families, the PI interviewed both of the BFs; the interviews provided a foundational understanding of the experience of surrogates who make decisions at the end of life from the point of view of the patient and family. The PI taped the interviews, transcribed them verbatim, and made an initial interpretation in which she searched for meanings and descriptions of the BFs' experiences.

In a second interview with each BF, the PI and the BFs reviewed, discussed, and confirmed the PI's initial interpretations. These interviews were rich in reflection and questioning, and the new interpretations were included in the understanding of the experiences of the BFs. The interpretations of these interviews were used to create rich narratives about the experiences of the BFs and to prepare guides to use in the interviews of the PSs. The interviews provided points of reference and comparison and areas for further probing in the PS interviews.

The initial interviews with each of the six PSs were conducted as described in table 1. The second interviews provided an opportunity for reflection, questioning, and new interpretation. The new interpretations were shaped into a more comprehensive understanding of the PS's experiences. Benner suggests, "the researcher needs to make explicit as many assumptions as possible prior to the beginning [of] the study and establish boundaries to the lines of inquiry for the study, but these must be held tentatively and allowed to be challenged, altered, extended and transformed by what is learned in the field."[31] It is important to have a broad understanding of the global "world" that is being studied, and, through the process of interview and interpretative analysis, to gain a richer understanding of the experience or phenomenon.

A qualitative research advisor who was familiar with the ICU environment, the experiences of families at end of life, and with interpretive phenomenology reviewed a random sample of the transcripts to validate, confirm, or challenge the PI's interpretations of themes.

 A final narrative was created from the interpretations of the interviews of the BFs and from the confirmed interpretations of the PSs. As Benner suggests, the reflection process included "continual interpretation of the similarities (pattern recognition) in each experience and the need to be attentive and responsive to the unique features of every individual case."[32]

RESULTS

CHARACTERISTICS

The participants in the study ranged in age from their early twenties to early eighties and were wives, husbands, daughters, sisters, and mothers. Their occupations were varied—some were students, some re-

tired, and some continued to work inside and outside the home. The subjects struggled alongside their family members through both chronic illnesses that had lasted many years and acute episodes that were unexpected. In some cases, the two overlapped (see table 2).

THEMES

All of the participants felt that they had had a role in making decisions. There were differences in what they thought their role should have been and what type of decisions they should have been included in, but they felt that it was their responsibility to be involved. The role of the surrogate is not an easy one; several issues arose that are common to many of their stories. Prior to presenting the main body of results related to making decisions, we will present these common issues as reflections the subjects shared about the whole decision-making experience.

Four separate themes arose from questions or concerns of the participants, questions such as, "Did I do the right thing?" or concerns related to personal struggles to "set aside one's own beliefs," "to hold onto the 'whole' story of the patient," and "to maintain the dignity and identity of the patient throughout the last days of life."

"Did I Do the Right Thing?"

The haunting question, "Did I do the right thing?" was mentioned first and most often by surrogates. One person stated, "You want at the end to not 'wish that maybe we should have,' there was none of that," (Interview BF1, l. 1457). Another participant reflected, "Because in this case, you don't want to be wrong. Otherwise, you know. The thing I love most in my life I don't want to kill it. So that's the part that really I agonized over a lot. Even after it had been done, it was, it was still agonizing. To figure out. Maybe you did. You know you question yourself. You say, did I do the right thing? Did I do the wrong thing?" (Interview 6, l. 798-826). The participants' phrases seem to reflect their internal moral struggle to balance their decision-making role with their emotional struggle as family members making decisions that have major implications, including potential losses, for both the patient and the family.

The Struggle to Set Aside One's Own Convictions

Several of the participants described the struggle of trying to set aside their own beliefs during the decision-making process. There seemed to be a sense that even if they didn't agree with the decisions of the patient or weren't able to accept the timing or the determination of the patient, the duty of the surrogate was to set these feelings aside and focus on the wishes of the patient.

Some felt torn between their desire to hold on and their need to let go. A participant who had cared for her husband at home through the ups and downs of a chronic, degenerative illness talked about how difficult it was to accept that her husband was ready to "give up." "I said, 'Don't talk like that, you're just weak. You don't eat.' And then he said, 'No, I'm not getting out of here.' So that's when I realized that mentally he was prepared too. But I still didn't want to admit it," (Interview 3, l. 348-352). They had already fought through so many difficulties, so it seemed that there was still time to continue to fight. The struggle occurred when the patient and the surrogate did not share the same perspective on the need or the willingness to continue.

The Struggle to Hold onto the "Whole Story of the Patient"

Family members often felt that they were the only ones who "had the whole story" of the patient. The environment in hospitals is chaotic, due to changing staff, shortage of beds, and frequent transfers. Surrogates reflected that these factors interfered with professionals' ability to provide the kind of care that families and professionals wish for. One of the concerns that many of the participants talked about was to keep both family members and professionals focused on the patient. Family members felt this was a crucial role for them. Problems were often related to the number of people who were involved, the volume and types of information that needed to be shared, and the potential for misinterpretation. Some talked about professionals who did not seem to take the time to find out what was most important to the family.

Vigilance on the part of the surrogate in carrying and sharing the information and the values of the patient were part of the focused approach described in this response: "She had over 100 x-rays and every time she went in they never had the total package. They didn't know whether it was her first or her one-hundredth x-ray," (Interview BF1, l. 155-158). Another subject described the role of the surrogate as "keeping everyone informed; reporting to everyone in the family and dealing with family members who 'second guessed' everything you said," (Interview BF1, confirmation interview). This type of vigilance requires emotional energy at a time when many were feeling overwhelmed and fatigued; the participants described themselves as shocked at this time and almost numb.

Maintain the Dignity and Identify of the Patient throughout the Last Days of Life

Some of the patients had been completely independent prior to the sudden onset of illness but regained neither consciousness nor the ability to make decisions once they entered the hospital. Their family members were clear that they needed to have an important role. Other family members watched their patient go through a gradual loss of function. These families struggled not against the role of being a surrogate, but rather against taking on the role either too soon or unnecessarily. There was a sense that individuals must be allowed to maintain their ability to be independent as long as possible. Part of the surrogate's role was to support this independent thinking and take over only when there were no other options.

One subject described the many ways that she and her husband had tried to hide his deteriorating condition from their children, to prevent them from seeing him in a diminished state. "They hadn't seen their father . . . since April. Their father, we could tell he wasn't well. But my husband for my children's sake was making believe," (Interview 3, l. 762-769). In their day-to-day life, the patient and his wife had also created different roles and reorganized their way of functioning as a couple, so that the patient could retain some of his independence. The patient's wife described the role: "He was doing all my transactions, my arrears, my bank transactions everything. My insurance . . . you know in other words he was all there. . . . It became the role that he had taken on even though he couldn't do the physical. It kept him going through all those years; otherwise I think he would have gone a long time ago," (Interview 3, l. 101-4; 967). Describing the situation after her husband died, the subject said that although this had been somewhat of an illusion, struggling to keep up a brave front allowed her husband to have a sense of dignity. She said that it was important to make sure that she didn't take over any roles that he could still manage if he was to maintain his feelings of self-worth.

These four themes represent the psychological environment of the participants during the process of decision making. The next section focuses on the process of making decisions on behalf of another at the end of life.

MAKING END-OF-LIFE DECISIONS

The process of making end-of-life decisions is complex. The interpretation of the interviews suggests that the process seemed to follow a series of steps. The steps can be described as "struggling to understand," "coming to terms," "transforming reality," and "needing to find peace with the decisions."

Struggling to Understand

Surrogates' struggles to understand involved more than just receiving information. Participants were often frustrated that both the amount and type of information provided to them made it difficult for them to understand: "and again I just, the terminology used for the layman is not, not that simple," (Interview 6, l. 1387). Several participants felt that there was too little information; this sometimes led them to feel that information was being withheld or was purposely made obtuse. "It was very hard to have faith. I like to, I'm a person who likes to be informed. Ignorance is not bliss. And I find that professional people tend to not to go into it deeply because they figure you're too ignorant maybe to understand and I think it's the wrong thing to do. They should be very candid about expressing in layman's terms the scenarios, that the person gets enough information to make an educated decision," (Interview 6, l. 553-64). This participant found it hard to

understand because the information received did not satisfy the participant's need for a certain type of information.

Another participant described the responsibility to share information as difficult because the participant was afraid that he did not understand what was being said: "I said to the boys, 'I don't want to tell you anything. I want you to come though, come by, see her, and we'll talk to the doctors. The doctor's gonna give [the news]. There's many things maybe I lost or something.' So we went there and we went to see the doctor and after that they called their sisters," (Interview 1, 882-886). It was important for the family members to not only "get" the information, but also to try to understand what the information meant, both now and for the future.

Depending on the type and the quantity of the information they received, some participants searched for more information from other sources. Several used the internet, some sought second opinions from physicians known to the family, others relied on information from colleagues or friends who had been through similar situations. Most were disturbed at having to seek out further information in these ways, but felt that they could not make sense of what professionals were saying if they did not have what they considered to be appropriate background information. On the other hand, some participants felt that they had received information that was useful and understandable. "It helped—the way they approached me. They put the facts on the table. They really told you the pros and cons," (Interview 3, l. 1045).

Those who received information that they perceived as adequate moved more quickly toward digesting the information and getting ready to make decisions. Digesting the information included thinking about and trying to make sense of it. Those who did not receive enough information searched until they were satisfied with their understanding and then began to digesting the information.

Coming to Terms

Once participants had received and digested information, a second step had to be accomplished before they moved to making decisions. In every situation, there was a process of coming to terms with the diagnosis and prognosis, in other words, recognizing the reality of the information and its implications.

Participants found it difficult to accept a diagnosis or a prognosis of such profound meaning. They described needing to be present to "see what the professionals are seeing" then beginning to "match" the words that were being said by the physician with their own vision of the patient. "When [the doctor] told me she was paralysed he said, 'the brain is a funny thing.' Her brain doesn't tell her that she's paralysed. She doesn't know. It was true. She didn't mention that. It never comes that 'maybe I'm paralysed' or 'I can't move my arm'. . . . She never, never mentioned that. This was helpful—I knew she wasn't worrying about that," (Interview 1, l. 1124-30).

Because of the shock and the disbelief, the participants often had difficulty reconciling the professional's perceptions of the patients with their own. "Well she's on life support systems, but all the reflexes are the wrong reflexes. She can't hear. She can't see. And she's totally nonresponsive . . . she's got a tube down her throat. She's hooked up. She's got a catheter. A tube coming out of her head. And she's staring into space. Otherwise she looks perfectly healthy, radiant, and relaxed. Four hours ago we were talking," (Interview 6, l. 157-74).

The perceptions of the surrogate had to be translated into new beliefs about what was happening to the patient and what that really meant. This was not always easy; because some participants felt that the messages they received were mixed, they were reluctant to believe what they heard. For example, one daughter was very skeptical when the physicians told her that her parent would die. There had been a previous experience in the family in which death had been predicted and yet the patient recovered. "The man recuperated incredibly. I mean look there's a photograph of him after his last illness. . . . He was ready to travel again. There was nothing, besides the fact that he walked with a walker, he was terrific. His brain was there. He knew us. He remembered stuff and he was fine. And you were wrong and we were right. So I mean you may know the medicine but we know the man," (Interview 2, l. 99-101, 109-115). The family was hopeful that a similar recuperation would be possible.

Another family struggled because the messages from both the patient and the staff did not seem clear. "He bled five times out of those arteries and still recovered. My sister went in . . . and found him in a pool of blood . . . but again he still recovered. I would always call and ask what his blood pressure was like? Stable, stable, stable!" (Interview BF1, l. 1081-83). The participant was unable to believe that the patient was really going to die because he had defied death so many times.

Most of the participants found that having the opportunity to talk to others, often those in waiting rooms who were going through similar experiences, and especially to their own family members, made the job of accepting the diagnosis and prognosis, if not easier, then somewhat more secure. When extended family members had not yet been involved, it was at this point they were called and asked to come to the hospital. When they were already involved, part of the process seemed to be ensuring that everyone had the same ideas about what they were seeing. "It's tough but when he stopped talking completely that's when I said there's something bad. So this is where we called my son in St. Louis and so forth. And from that point I realized he was going," (Interview 3, l. 356). Family talks often involved discussion about who the person had been in the past and who the person was expected to be now.

Several factors contributed to "coming to terms" with what was happening. If the family had already had a previous experience in which the patient recovered despite dire predictions, the "matching" process could be hampered by a real reluctance to believe that this time would be any different.

Pre-existing conflicts within the family left participants feeling isolated and alone. The "aloneness" heightened participants' sense of fragility and, in one situation, it caused a participant to recreate, through pictures, the family that no longer existed because of divorce and acrimony. "So I brought the flowers in and I felt like the others should have been there. Like I was really mad that they didn't come down. So at least I brought a picture and I put it by her bed . . . pictures of the family and the cat. . . . And I guess it made me feel better. I don't know if it helped her but it made me feel better," (Interview 5, l. 680-690). The "aloneness" created by conflicts left the participant with no one to talk to about the patient and no one to support the participant, who had to make the decisions.

One of the participants had past memories of conflicts with the patient that had not been resolved. The patient was unconscious from the moment of admission and the surrogate was aware that there would be no opportunity to discuss the resentments and lingering anger. The participant reflected that there had always been the hope that there would be time to have the discussions. A friend had suggested that the participant attempt to talk to the patient even though the patient could not respond in any way. Even after trying this, an empty feeling remained because there was no way to solve the problem. This made the process of saying good-bye even more difficult.

Most of the participants discussed the role that the shock or the emotional impact of the incident played and how they felt paralyzed or numb. The raw emotions often prevented them from being able to hear or to think straight. "The whole time with my brother, I don't think any of us ever expected this end. We were totally unprepared. I never even talked about advance directives. We were going to get to it after the crisis," (Interview BF1, l. 1381-2). "We didn't, we didn't expect that because it happens so fast, we didn't see it come," (Interview 1, l. 22-24). In both of these situations, emotions had an impact on the participants' abilities to recognize and accept what was happening—the ongoing process for the participants of matching what they heard with what they know.

Many of the participants had had an opportunity to discuss end-of-life wishes with the patient at some point in the past. In every family in which this had taken place, the discussions were seen as very helpful to the surrogate as they struggled to "come to terms."

Transforming Reality

Once the process of "coming to terms" with the diagnosis and prognosis had been accomplished, a process of "transforming reality" began. Once the participants understood the diagnosis and the prognosis, they could understand a new reality—that there was no turning back. The patient was dying, or would no longer be able to recover.

In the earlier process of coming to terms, there was a need to match the words that were said by the physician about the new reality of the patient with the participant's own beliefs. Once participants understood the new reality, a second process of matching began. Family members had to match their understanding of the new reality (the patient cannot live as he or she is) with their perceptions about who the patient was and whether or not the patient would accept the new, predicted future.

Some of the participants described how their patient had been in excellent health, but then experienced a sudden, catastrophic illness that had ended the patient's life. Other patients died following many years of living with a chronic illness and its ramifications. Participants whose patients suffered from an acute, catastrophic illness experienced a shock of going from "absolute health to death," (Interview 6) that was so overwhelming that they had trouble transforming reality. Participants whose patients survived a chronic or long-term illness described a need to shift their thinking from "fighting to survive so that they could continue to live" to "finding a willingness to let go." One of the participants described her struggle to identify the difference between her past need to be aware of signs and symptoms of the chronic illness and a new need to see new signs and symptoms as indicative of the approaching end of life. Another facet of chronic, long-term illness was an inability or unwillingness to think about death. One woman reflected that, despite the multiple problems that existed, she and her family had never even thought that death would be the outcome. There had been no discussion with professionals about this possibility either, even though the patient had suffered from a progressively deteriorating condition.

In each of the study interviews, the participants felt able to say what the patient would have wanted and, in several cases, there had been opportunity for the patient and the surrogate to talk together prior to the illness or injury that finally caused death. "I knew from before, like my mother always told me 'Do not keep me alive by machine.' So like I knew, I agreed with the doctor right away that that was the right thing to do," (Interview 5, l. 278-280). Knowing the patient's wishes made an emotional situation less difficult.

The difficult aspect of this part of the decision-making process was being sure that this was the right time to stop. Even when a surrogate accepted the reality of no return, it seemed important to be sure that every chance had been given and no question had been left unasked. A final step in transforming reality was the struggle to identify which limits or deficits the patient would have accepted, and then knowing that the time had come for treatment to stop. Participants described their discussions with physicians at this point as confirmatory or agreement-seeking: "If he had been absolutely fine and his surgery had worked really well . . . it would have been a totally different situation. But that wasn't the situation. The situation was—his quality of life stank. Four days and not a flicker of change. And the fact that his quality of life was so rotten and that he had metastatic disease. This looked like it was time for it to be the end," (Interview BF1, l. 890-899). Being able to identify that a "bottom line" had been reached made making the decision to stop treatment more palatable.

It seems as if making a decision was less emotionally significant than the complicated processes of coming to terms, transforming the reality, and identifying the end. When these steps had been accomplished, the decision, although still emotionally difficult, seemed clear. Making the decision seemed to be the end result of the transformative reflection. Participants did not speak about making a decision as separate from the reflection, but more as part of the process.

Needing to Find Peace with the Decision

Many participants said that after they made a decision to stop treatment, they needed to find peace with the decision; they did this in different ways. Some participants confirmed their decision with others: "So after his best friend listened to the doctor [and knew that] we gave our decision I said, 'What do you think? Did we do right?' He says, 'My dear, I'm not his brother but I think you did right. I know him. He'd never want to accept this'," (Interview 3, l. 1335-47). For one person it happened through being present during the withdrawal of treatment. This person was able to confirm the decision made by seeing that what was predicted actually happened. Through this process the participant came to feel that the decision made had been the right one. "If she dies then she's meant to die . . . so they stopped the machine. My wife didn't, she lay

there immobile. And I watched the heart monitor and within about seven minutes the heart stopped," (Interview 6, l. 280-2; 305-7). Death was confirmation that life could not have continued without machines, a life that the patient would not have accepted.

Others talked about how they finally realized that the life that had been predicted would not have been acceptable to the patient; this was important in being able to find peace with the decision that had been made. "It's much better than if he'd had more metastatic disease and was in palliative care in pain for months, conscious—knowing he was dying. That would have been brutal. I can see him jumping out the window," (Interview BF1, l. 906-8).

For many participants, the loss of the patient was their first experience with death. Experiences with death, similar to experiences with making decisions, were often affected by the participants' preconceptions, their relationships with others, and their ability to understand what was happening. Several remarked that the death, as it happened, didn't match what they thought it would be like. "My expectations were that it would take much less time. I didn't think she'd hold on for a day. And when she did start to slow down, it shocked me that it was so sudden. So like I thought it would take maybe, it would be a steady decline, for maybe a couple of hours," (Interview 5, l. 611-13). Participants said that they found it difficult to interpret what was happening and their role in it because they didn't know what death would be like. For example, one surrogate talked about how the uncertainty surrounding the dying process, which lasted several weeks, made the family's goal to be with the patient at the time of death very difficult to achieve. The difficulty of dealing with both the hospital environment and the vision of the patient, head shaved and covered in tubes, was mentioned by another participant as part of the struggle to find peace with the death.

Others talked as if they were trying to turn the situation over and over in their heads in some way, in an effort to begin to come to terms with the death. Their words were a reflection of the conversation that was going on inside their head: "There is no easy way for this process to run its course because the facts are so strong. And overwhelming. You know the diagnosis of the person, not being able to survive because medically they're dead. . . . It's just the evidence is so strong there . . . the process [of finding peace with the death] comes after the fact. I think because it's the process to find a place to put it that you can live with it," (Interview 6, 1. 140-1152). Many participants stated that they continued on a daily basis to try and make sense of what had happened and to find peace with the decision that they had made—and the interviews were approximately six to seven months after the death.

Some of the participants were not present at the time of death, yet the same processes of finding ways to come to terms both with their decision and with the death occurred. One participant whose experience had been particularly difficult was not present during the time of her father's death. In her reflections after the death, she felt that, given the circumstances, this had probably been a good thing. For her, witnessing the death of her parent would have made the situation even worse. In contrast, another participant who had been closely involved in every aspect of the last few months of treatment, surgery, and complications found that missing the actual moment of death made her feel as though the experience was incomplete. She remembered going over every detail with the family.

One of the participants' experiences was significantly different from the others. She described the situation as the worst experience of her life. She felt that the staff had completely misinterpreted the essence of her family and their values and beliefs. Much of the conflict sprung from a belief on the part of the participant that there was no relationship between the staff and the family. This lack of relationship with the staff and the staff's lack of understanding of the family's culture and beliefs was coupled with a very wooden approach from the staff, which the family found disgusting. The participant described one of the professionals by saying: "She obviously just knows how to deal with a certain type of person who's raised in a certain type of way. And no other. Just get her away from me," (Interview 2, l. 493-96). The family had a fundamental belief that they did not want to be involved in certain decisions about death; the very conception of such decision making, to them, seemed wrong: "I think that's where my bitterness lies. Because I didn't feel like I . . . wanted to be pushed that way. I don't think there were any decisions to be made," (Interview 2, 1. 332-343).

From the perspective of the staff, a family who felt this way might be labelled unrealistic. It is clear, however, that both the participant and her family understood that death was likely to come soon; they had even requested that there be "no resuscitation" in the event of a cardiac arrest—a very clear decision had been made and articulated by the family. They simply believed that it was wrong to be involved in decisions about allowing someone to die—the decisions they had made were the only ones that they could make—the others were "up to God not doctors," (Interview 2, l. 362). As a result of the very bad feelings between the staff and family, the perception of the participant was that the staff were deliberately cruel because the family didn't want to follow the usual process.

There was a profound clash of cultures—the family culture and the healthcare culture—and the result of the family's traumatic experience was that, at seven months after the death, the participant had not yet begun to come to terms with her parent's death. She did not go through the same thinking processes that had helped others, even in their sorrow, to be prepared for death.

DISCUSSION

Participants talked about their role in end-of-life decisions as a process, not as something that happened at a single point in time or as a task. Participants talked about the thinking they had done, the reflections that had haunted them, their fears about not knowing what was "the right thing to do," and their incredible sense of loss. While grief might be described as learning to live with loss, the processes taking place in these interviews seemed to be "pre-grief": a recognition that loss was coming. The surrogates were struggling to come to terms with the fact that the patient would no longer be part of their lives.

Our aim in doing this research was to understand the cognitive and emotional processes, the lived experiences of surrogates during the process of making decisions at the end of life. We examined four specific points from this body of work: the significant shifts in understanding during the experience of being a surrogate, the surrogates' experience as a challenge to identity, a re-examination of meaning, and, finally, an examination of what professionals can learn through the experiences of surrogates.

In both the "coming to terms" and the "transforming reality" concepts, there were mentions of "matching processes." Drawing on his work on cross-cultural discourse, Taylor describes a "fusion of horizons" which, in the "coming to terms" process, might be translated as the recognition, on the part of surrogates, of the meaning of what is being said, and, on the side of the professionals, of a state of certainty that may lead to a place of no turning back.[33] This fusion requires, at a minimum, a recognition of the world in which the other exists. Akin to this fusion—perhaps a precursor to it—matching might more aptly be described as a "dawning of awareness." The dawning of awareness that takes place during the process of "coming to terms" seems to symbolize a cognitive, emotional, perhaps even spiritual awakening to further cues to come. At this stage, it is almost as though there is an awareness that the day has dawned, but there is no certainty yet what the day will bring.

Just as dawn gives way to the harshness of full daylight, each participant was presented with a new, grim reality. During a time of transformative reflection, participants began to understand that the patients would not be able to survive as the persons they were before. As the dawning of awareness becomes reality, the horizons of surrogates and professionals must become more intricately entwined, to enable the surrogates' transformative reflections to lead to a convergence of the "physician-predicted future," with the expectations or hopes that the family members brought with them. Ultimately, the "transforming of reality" and the process of transformative reflection continues throughout the dying and into the grieving.

A second point of interest taken from the data suggests that the intellectual and emotional struggle facing surrogates may be representative of a challenge, both to the identity of the surrogates and to their concepts of family. The transformative reflection process involves trying to understand a set of clinical data that will ultimately result in the complete transformation of one's world. Not only are the data, as discrete packets of information, often complex, but the ramifications they present embody a very fundamental challenge to the expression of one's self-concept in relation to one's world. Taylor suggests that people develop their identi-

ties based on the culture, ideals, history, and behavior that have been developed through their relations with their immediate world or family.[34] When one associates one's personal identity with a certain constellation of family members, it is understandable that a permanent loss through death can precipitate an identity crisis. Am I still a wife if I no longer have a husband? If my husband is dead, does he completely cease to exist in me? Will memories be enough to keep alive what he has meant to me?

Through the "coming to terms" and the "transforming reality" processes, participants were able to begin their explorations of their past world, compared with their present reality. In some cases, they moved toward a new future without the patient as a physical member of their world. In coming to terms, participants acknowledged that the relationship that existed was altered forever. In the phase of transforming reality, the very significant step of examining who the patient has been in the past in relation to who the patient will be in the hypothetical predicted future, while trying to determine whether the patient would or would not accept the assigned fate, can become an overwhelming burden.

Taylor would suggest that part of the burden comes from having to discover if one can exist with one's new vision of self that does not include the person who has died. In fact, he would suggest that despair or breakdown will be the result when one is not able to reconcile the loss and discover a new vision of self or a new personal identity.[35] One might consider that the struggle to understand information, the questioning, the confirmation through conversation about the decisions made, and the discussions about who the patient was prior to the illness and injury, all reflect the processes of deconstructing and reconstructing not only the identity of the patient, but of the surrogate. Being alone, having previous conflicts in the family, and previous illness experiences or conversations with the patient are factors that affected the process, acting either as facilitators or hindrances. The one participant's radically different story reflected a transformation process that was arrested by an inability to come to terms. The most significant factor communicated to the researcher by the family was the lack of a relationship with the healthcare team, and what the family perceived to be the staff's fundamental misunderstanding of the family's "identity" as a family. This misunderstanding on the part of the team led to a mistrust by the family so profound that the process of transformative reflection was inhibited—in fact, it was arrested.

> Without words, it comes. And suddenly, sharply, one is aware of being separated from every person on one's earth and every object, and from the beginning of things and from the future and even a little, from one's self. A moment before one was happily playing; the world was round and friendly. Now at one's feet there are chasms that had been invisible until this moment. And one knows, and never remembers how it was learned, that there will always be chasms, and across the chasms will always be those one loves.[36]

This brief and poignant excerpt from Lillian Smith's "The Journey" give voice to the painful transformations that take place through death and grieving. In our study, it is clear that the transformative reflections began with the dawning of awareness that one's world was about to change and led to some distant and undefined point in the future.

The concept of meaning is a third point of interest. Taylor says meaning is created through language, through which we seek words to express who we are, how the world—our world—is unfolding, and how we can make sense of it.[37] The need to have a language that can describe what is occurring is essential. Yet, when one is suffering, it is difficult to find the words to express the experience or to create a narrative. Younger goes so far as to suggest that suffering attacks one's world and one's self, actually destroying one's ability to communicate.[38] What has been described in this study as transforming reality would be described by both Taylor[39] and Younger[40] not only as reconstructing an identity, as described above, but also as reconstructing the narrative, to create some sense of meaning through words. Being able to make decisions seems to be linked to an ability to create this meaning and to begin the process of living with a reconstructed, although naïve, identity (which will continue to be reconstructed throughout the grieving process).

The final point for reflection examines the role of healthcare professionals. Much of the processes of "coming to terms" and the "transformation of reality" appear to be internal struggles that surrogates must

conquer alone. However, before transformative reflections could assist surrogates, participants in the study indicated that there was a need to understand and translate information from professionals into something they could understand and handle. Transformative reflections can be facilitated or hindered by the approach, the language, and the compassion of the team that assists surrogates. Most models in the literature include an interconnected approach, in which understanding the illness process and making decisions based on a patient's values and beliefs are emphasized.[41] The promotion of a "good" understanding of the trajectory of illness and of the expected outcome is well-defined, but understanding and facilitating the translation of a patient's values and beliefs to meaningful decisions is not as clear.

Our illumination of surrogates' experiential reflections can help clinicians to tailor their explanations and their discussions, which can assist surrogates in their process of transformative reflection. When clinicians remember that surrogates process information differently, clinicians are able to understand that they should assess each surrogates' preferred method of exchange. This involves understanding how surrogates use language and understand and interpret medical facts. When clinicians begin the communication process by probing exactly what surrogates understand, this action allows clinicians to identify the language that the surrogates use. Clinicians then can use similar language to address inaccuracies or misunderstandings and to begin the process of assessing the level of distress present. The use of a team approach ensures that information will remain consistent and that physicians and nurses remain connected, sharing reflections and assessments of the surrogate and the support that is needed and provided.

As clinicians work with surrogates, it is useful for clinicians to understand that the dawning of awareness signals or triggers a process of coming to terms and transformative reflections. When surrogates are in the process of coming to terms, clinicians can probe the surrogates' perceptions and discuss their beliefs about what is happening and why. Most importantly, clinicians can consider the particular context, or world, of the patient and his or her surrogate, as that world defines who the surrogate "is" and how the surrogate's identity is challenged by his or her present circumstances. This is key in the phase of transforming reality. Drawing on this information about a surrogate's context will allow clinicians to prompt discussions that reflect a convergence of the past, the present, and the expected future of the patient, with a clear and honest reflection of the prognosis.

These forms of interaction require an engaged and compassionate approach. Participants showed a strong need to feel that members of the patient's healthcare team cared about them, and that their relationship was honest and sincere. While this may be a challenge, given the chaotic and fractured systems within which most clinicians work, re-orienting how information is shared and the discussions that ensue facilitates an authentic partnership between professionals and surrogates. Finding even simple ways to demonstrate compassion by approaching the patient and the surrogate with dignity and respect, by the judicious and sensitive use of touch, and by attending to the emotional needs of the surrogate through a team approach will enhance the relationship and help to diffuse or diminish some of the anxiety that is bound to be present.

Understanding the complexity of the processes that surrogates must face accentuates the difficulties of fulfilling the role of substitute decision maker, as currently defined in the bioethics literature. Our findings provide some new ideas on how a professional's approach can facilitate or hinder a surrogate's ability to fulfil his or her role. Attending to how information is interpreted and the ways that surrogates use and process information assists clinicians in providing appropriate and supportive interventions, so that surrogates can make decisions that are more congruent with those of the patient.

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