

Planification préalable des soins : la révision de notre approche éthique

Carole A. Robinson

Cette étude qualitative a exploré l'applicabilité et l'utilité d'une intervention de planification préalable des soins (PPS), et examiné le processus de PPS. Neuf dyades (des patients et patientes auxquels on a diagnostiqué récemment un cancer du poumon à un stade avancé et un membre de leur famille) ont participé à l'intervention de PPS, ainsi qu'à des entrevues évaluatives effectuées trois mois et six mois après l'intervention. Toutes les entrevues ont été enregistrées, transcrites mot à mot et analysées à l'aide de la méthode de la comparaison constante. Il a été constaté que le processus ne préparait pas un mandataire spécial à parler en son propre nom ni à orienter les soins de santé dans la situation où une personne est incapable; il engageait plutôt les familles dans un processus relationnel très profond permettant de discuter de la signification, des valeurs et des préférences. En théorie, la PPS repose sur la notion traditionnelle de l'autonomie du patient ou de la patiente, laquelle n'est pas en harmonie avec le processus relationnel qui s'est manifesté dans cette étude. Une approche qui épouse l'autonomie relationnelle est plus congruente et fournit une base plus solide pour répondre aux besoins des familles.

Mots clés : planification préalable des soins, éthique, autonomie du patient, autonomie relationnelle

Advance Care Planning: Re-visioning Our Ethical Approach

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This qualitative study explored the applicability and usefulness of a promising advance care planning (ACP) intervention and examined the ACP process. Nine dyads (patients newly diagnosed with advanced lung cancer and a family member) participated in the ACP intervention, with evaluative interviews at 3 and 6 months after the intervention. All interviews were recorded, transcribed verbatim, and analyzed using constant comparison. The process was found not to be one of preparing a substitute decision-maker to speak for oneself and direct health care at a time when one is incapacitated; rather, the families engaged in a deeply relational process where meaning, values, and preferences were negotiated in conversation. ACP is theoretically rooted in a traditional notion of patient autonomy that is not aligned with the relational process that unfolded in this study. An approach that embraces relational autonomy is more congruent and provides a stronger foundation for meeting the needs of families.

Keywords: advance care planning, ethics, patient autonomy, relational autonomy

“Advance care planning is, at its most basic, a process of thinking ahead to treatment choices, goals of care, and/or choosing another person (proxy) to speak for oneself at a point in the future” (Romer & Hammes, 2003). While Romer and Hammes state that discussions of advance directives and advance care planning (ACP) are omnipresent in the end-of-life literature, and while these initiatives have received a great deal of attention over the last two decades in the United States, the Canadian health-care system is just beginning to systematically communicate on decision-making at end of life (Carstairs, 2005). Limited public awareness of ACP, lack of integrated services such as ACP, varying provincial legislation, lack of leadership, and reluctance to discuss death and dying — even among care professionals — present continuing challenges to care at end of life in Canada (Carstairs, 2010).

The promotion of advance directives as a way for patients to control their own medical care should they become incapacitated is associated with the 1990 US *Patient Self Determination Act* (PSDA) and subsequent accreditation standards (Emanuel, 2008; Romer & Hammes, 2003). The PSDA requires hospitals, nursing homes, and health plans to ask whether patients have advance directives and to include these in the medical record. As a result, most US health-care organizations provide some assistance with the completion of advance directives. However, the original

document-driven approach to ACP has met with strong international criticism and marked lack of success (Kass-Bartelmes & Hughes, 2003; Solomon, 1999; The SUPPORT Investigators, 1995). Two challenges have become evident: completing the documents and getting them on record, and having the stated preferences influence care (Collins, Parks, & Winter, 2006). These challenges are exemplified in the landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), a large prospective clinical trial designed to improve end-of-life decision-making (The SUPPORT Investigators, 1995). The intervention included the use of specially trained nurses to facilitate conversations and information exchange among patients, families, and physicians. While demonstrating a significant increase in documented advance directives, the intervention did not improve communication, incidence, or timeliness with respect to “do not resuscitate” orders, days spent in the intensive care unit, physician knowledge of patient preferences, or level of patient pain. In other words, the intervention failed to improve end-of-life care. The document-driven approach is severely limited by a narrow focus on specific interventions and lack of attention to the broader values and goals of care that accurately predict end-of-life treatment preferences (Collins et al., 2006; Emanuel, 2008; Kaldjian, Curtis, Shinkunas, & Cannon, 2009). As well, the influence of advance directives on care continues to be limited by procedural, legal, and communication difficulties (Collins et al., 2006). Further, end-of-life values change over time and there is a risk that advance directives will not reflect related changes in treatment preferences, since the document may not be revisited (Collins et al., 2006).

In response to the failure of ACP to improve end-of-life care, the field has evolved from a legal, document-driven one to a process of engaging patients, families, and substitute decision-makers in conversations about hopes, wishes, values, and goals with respect to care. In contrast to earlier initiatives, this process orientation to ACP has demonstrated success in improving end-of-life care (Collins et al., 2006; Hammes & Romer, 1999; Lorenz et al., 2008). ACP, when done effectively, is associated with meaningful outcomes for patients, including a sense of well-being, connection with family, sense of control, peace of mind, relief of anxiety, and relief of stress for proxy decision-makers (Briggs, Kirchhoff, Hammes, Song, & Colvin, 2004; Clayton, Butow, Arnold, & Tattersall, 2005; Ditto et al., 2001; Kass-Bartelmes & Hughes, 2003; Martin, Thiel, & Singer, 1999; Sakalys, 2003; Singer et al., 1998; Stewart, 1995; Tilden, Tolle, Garland, & Nelson, 1995; Tilden, Tolle, Nelson, & Fields, 2001; Tulsky, Fischer, Rose, & Arnold, 1998). Since most of these outcomes arise from the effectiveness of the process rather than from the completion of doc-

uments (Briggs & Colvin, 2002), skilled facilitation and engagement of key decision-makers is critical (Lorenz et al., 2008).

The thinking about ACP in Canada has mirrored the shift seen in the United States (Carstairs, 2000). Further, ACP is viewed as integral to high-quality palliative care and is consistent with the values, guiding principles, and foundational concepts identified in the National Model created to guide the development of palliative care in Canada (Ferris et al., 2002). In relation to advance directives, the Senate Subcommittee to update *Of Life and Death* (see Carstairs, 2000) came to this conclusion: "If loved ones and medical professionals have engaged in a process of serious communication, the problems associated with the interpretation and application of advance directives are much less likely to arise. The passage to death is eased, the level of comfort rises, and the burden of care is lightened for the substitute decision maker." Yet, while 83% of Canadians feel it is important or extremely important to discuss their medical care wishes with family members, only 44% of those surveyed had had at least one discussion with a family member about ACP (Ipsos-Reid, 2004). The Senate report also points out that legislation pertaining to advance directives varies across Canada, which creates a set of problems, and that our orientation to advance directives as opposed to the process of ACP is associated with problems of interpretation and application in the often ambiguous situations of real life. Again, these ideas mirror the findings reported in the United States.

Despite the shift towards ACP as a process that requires the involvement of persons who are significant to the planner, the ethical foundation of ACP remains firmly rooted in individual autonomy and the right of self-determination (Emanuel, 2008; Puchalski et al., 2000). ACP is viewed as a way of extending individuals' autonomy and control over future health-care decisions at a time when they may be unable to speak for themselves (Collins et al., 2006; The SUPPORT Investigators, 1995). This practice relies on substitute decision-makers who are charged with making choices the patient would have made (Hickman, Hammes, Moss, & Tolle, 2005; Shalowitz, Garrett-Mayer, & Wendler, 2006). Yet the evidence shows that this standard is frequently unattainable and may not even be desirable from the patient perspective (Collins et al., 2006; Emanuel, 2008). Indeed, many patients want their substitute decision-makers to use their own judgement rather than strictly follow preferences stated in an advance directive (Puchalski et al., 2000).

Consideration also needs to be given to the negative consequences family members may experience as a result of their involvement in end-of-life decision-making (Haley et al., 2002; Tilden et al., 2001; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999). One of the main goals of

ACP from the patient perspective is alleviation of the burden on family members (Martin et al., 1999; Singer et al., 1998), and family involvement in the process supports this goal (Tilden et al., 1999, 2001). While the importance of family involvement is evident, the role of family members in the ACP process has received little research attention beyond studies focused on the accuracy of proxy decision-making (Shalowitz et al., 2006). A model of shared decision-making has been proposed as one way to address family involvement, but it is unclear how this aligns with the foundation of individual autonomy (Collins et al., 2006; Kaldjian et al., 2009). How do we reconcile the traditional conceptualization of autonomy that values independence, self-sufficiency, and decision-making free from the influence of others (Mackenzie & Stoljar, 2000) with the recognition that ACP is dependent on an iterative process of discussion and feedback within a network of intimate relationships (Martin et al., 1999; Prendergast, 2001; Singer et al., 1998)? This apparent contradiction has the potential to cause clinical tension and raises further questions regarding the appropriate role of both family members and health-care providers in the ACP process. For example, Sahlberg-Blom, Ternstedt, and Johansson (2000) posit that “decision making concerning a dying patient can be described as a drama comprised of different conflicts concerning autonomy between a variety of actors such as the patient, the patient’s relatives, and caregivers” (p. 297). Here, emphasis is placed on competing needs that arise between independent and self-determining players rather than the interdependence that characterizes much of family life.

This article reports on an ethically and clinically important facet of a study focused on ACP in the context of a diagnosis of advanced lung cancer: the relational process. The patients and family members who took part in the ACP intervention demonstrated deep relational engagement that calls into question the ethical foundation of ACP and provides support for a shift in perspective. An approach that honours both autonomy *and* the intimate relationships in which it is embedded is discussed. The article is intended to provide insight into one way of better informing the ACP process.

The Study

The study was designed to evaluate the applicability and usefulness of a promising patient-centred ACP intervention developed by the Respecting Choices[®] program in Wisconsin (Briggs et al., 2004). The study was approved by the University Research Ethics Board.

The Intervention

A recent US development in ACP addresses special populations who, because of complex health concerns, need extra assistance and skilled facilitation in making future health-care decisions (Briggs, 2003; Briggs et al., 2004). This initiative, the Patient-Centered Advance Planning Interview (PC-ACP Interview) evolved as it became apparent that different ACP approaches are needed for different situations (Briggs, 2003; Briggs et al., 2004). Special populations include individuals with end-stage chronic illness. The hallmarks of the initiative are as follows (Briggs, 2003; Briggs et al., 2004; Hammes, 2003; Hammes & Romer, 1999):

1. A guiding ethical principle of respecting the patient's beliefs, values, and preferences.
2. A focus on relationships; thus, patients and their families are engaged together if possible. Family is defined in a non-traditional manner, to include those persons closest to the patient who would most likely offer support and be involved in decision-making.
3. Creation of an emotionally safe environment for discussion that is facilitated by a trained, highly skilled individual.
4. An educational approach whereby patients/families gain an understanding of realistic future options and associated decisions, have the opportunity to reflect on this information, work through the issues, come to decisions that are consistent with their values and beliefs, and communicate these decisions appropriately.
5. Information offered to the patient and family that is individualized to diagnosis, understanding, values, goals, and beliefs. Thus, it is disease- and situation-specific.
6. Pacing according to family direction about what will be discussed, and when.
7. A process orientation whereby discussions can be revisited over time.

A pilot study for the intervention (Briggs et al., 2004; Schwartz et al., 2003) reports the following outcomes:

1. Patients and their families were more prepared to make difficult decisions after having these discussions. Briggs (2003) found that patients were often afraid to talk to their loved ones about these issues and the intervention offered a valuable opportunity for discussion.
2. Less conflict among family members and enhanced confidence in decisions.
3. Significantly improved congruence, in specific treatment preferences, between patients and their surrogate decision-makers.

4. Significantly greater patient satisfaction with the quality of patient-clinician communication when compared to patients who had not had this level of discussion.
5. Significantly lower decisional conflict for patients about preferences for future medical care when compared to patients who had not had the intervention.

This promising evidence-based intervention was chosen because it showed potential for enhancing the quality of life and death for our chronically and terminally ill population. Further, we wanted to extend knowledge about its usefulness to persons with cancer and in a Canadian context. We were also curious about *how* it worked, since this had not been examined before.

Participants

The sample of 18 participants comprised patients newly diagnosed with advanced lung cancer and their chosen significant other. All dyads spoke and read English. Six dyads were married couples and three were parent/child (one son; two daughters); the patients in the three latter dyads were either widowed or divorced.

Of patients who are newly diagnosed with lung cancer, 80% will have advanced disease and require immediate palliative care. Those patients who are palliative from initial diagnosis often face a rapid decline in health, accompanied by an abbreviated time frame for decision-making, and early death. Median survival estimates for persons diagnosed with the dominant form of advanced lung cancer range from 5.8 to 7.3 months (Breathnach et al., 2001).

Data Collection

The PC-ACP is a structured interview with a consenting patient and a chosen significant other, delivered by a trained facilitator and lasting 1 to 1.5 hours. It is an opportunity for the patient and family member to consider the life-sustaining treatment choices the patient would make if he/she became unable to speak for him/herself. The purpose of the interview is to explore the patient's understanding of the situation, introduce new information as needed, and promote dialogue.

First, participants' experiences and beliefs about their life, illness, and treatment were explored; then the participants were led through a series of situation-specific scenarios where preferences for end-of-life care were elicited (see Briggs [2003] and Briggs et al. [2004] for a more detailed description of the interview components).

Where possible, evaluation interviews were conducted 3 and 6 months after the intervention, which itself occurred several months after

diagnosis. Follow-up did not take place with all families, for various reasons, the most common being illness progression. In total there were 15 interviews (nine PC-ACP interviews; six follow-up interviews). All of the interviews were audiorecorded and transcribed verbatim. Audiorecording of the intervention enabled in-depth exploration of the process, which had not been done before. The data also included detailed field notes.

Data Analysis

Constant comparative analysis proceeded concurrently with data collection (Glaser & Strauss, 1967). Two researchers with expertise in qualitative research independently read and reread the transcripts, identifying meaning units or themes. The codes evolved through the iterative process of constant comparison within and across transcripts and discussion between the researchers. A coding schema was developed by consensus and NVivo was used to manage the data. This article reports on the relational process of ACP.

Findings

The involvement of significant others in the ACP process was intended to enhance family members' understanding of patients' preferences so that they would be able to better speak for the patient, if necessary, at end of life and to reduce the burden of doing so. In other words, the aim was to prepare family members for their role as substitute decision-makers while also reducing the negative consequences, with the patient foreground and the family member somewhat in the background. In contrast, the relational process that unfolded was interactional, with family members actively engaged in both the narrative process and the decision-making process that followed. In each dyad, both the participants and their network of relationships were foreground.

The Narrative Process

The intervention began by eliciting the patients' narrative about their illness, including fears, past experiences with serious illness and death, and values and beliefs that were influential to their definition of quality of life. Family members spontaneously "jumped in" even when questions were explicitly directed to the patient. Family members reminded patients of things they had forgotten, finished the patients' sentences, elaborated on the narrative, initiated joint problem-solving when concerns arose, and offered their own ideas and experiences. Both members of the dyad frequently used the word "we" when referring to the illness experience — for example, "We were in hospital." The conversation

clearly showed that illness is a relational experience. In the following exchange the participants speak for each other and the relational impact of symptoms arises:

Researcher [to husband/patient]: *Any other areas of your life affected [by the symptoms]?*

Wife: *Not very much . . . he went to play poker last Wednesday night. [laughs]*

Researcher [to wife]: *And how about you? Do you see how [husband's] symptoms have affected his life?*

Husband/patient: *She has to do all the work.*

Wife: *[laughs] No, that's not true. Actually, as he says, he's back to doing stairs and we're going for walks every day.*

As this conversation illustrates, the patient-centred, individual focus of the questions was shifted towards a family-centred, relational focus by the participants. From the family perspective, the illness experience is a shared experience.

Family members often used the conversation to affirm the vitality of the ill person, to offer support, and to highlight the person's contributions to family life. This emphasis on the importance of the ill person's involvement in family life was a counterbalance to discussions about physical decline and dependence:

Husband: *One day I was out there in the yard digging and I looked in and she [wife/patient] was standing by the window there. I sneaked around after her and I came in this door and she didn't know I was coming in this way. And I walked in and the tears were going. And I said, "What happened to you?" She said, "You're doing my job." So I said, "Well, it was time. You've done it 50 years. It's my turn. You stand there and tell me what not to cut and rake."*

Researcher: *So there's been a fair bit of loss for you [wife/patient].*

Husband: *Oh, that's the problem. [pause] She still cooks a mean meal.*

In another interview, the family member was quick to point out his father's active contribution to family understanding:

Father/patient: *I don't know what I learned [from the mother's death].*

Son: *Well, you take a great deal of effort and care to make sure that everybody is informed.*

This reveals a process of mutual affirmation.

Patients also used the interview to acknowledge the closeness and importance of the relationship with their participating family members:

Mother/patient: *She [daughter] will be able to sense what I want, because we've been close . . . I'm really sorry for [my daughter] . . . I'm really glad she's here, but she's taking on a big, big job, a really big job. And she just moved here a year ago. She kind of figured we'd do a lot of things together, as we like to cross-country ski, and we did a little bit of that last year, and we were looking forward to doing things like going to hockey games and just doing things together. Now she's got my responsibility . . . she's got the full load.*

Daughter: *This is not about me, Mom. This is about you. [sobbing]*

Mother/patient: *It's about both of us.*

This conversation also illustrates how patients were worried about creating a burden for their family members, which became a point of discussion in many of the interviews.

The dyads demonstrated mutual support through family solidarity, particularly around hopes for the plan of care, as seen below:

Researcher: *Now, you [wife/patient] touched on this a little bit earlier . . . what do you hope for from your current plan of care?*

Wife/patient: *From my current plan of care . . . I'm hoping for recovery.*

Husband: *Complete.*

Wife: *Complete recovery.*

Another family said it this way:

Father/patient: *I don't think there are going to be any complications [of my lung cancer], to be quite honest. I don't.*

Son: *I'm with you, Dad.*

All of the patients identified family as what sustained them in difficult times. For most, this was the only support spontaneously identified.

Researcher: *Who or what sustains you when you face challenging times?*

Husband/patient: *For this condition I got now?*

Researcher: *For any challenges . . . if you think back . . .*

Husband/patient: *My wife of 50 years.*

When questioned further, some participants expanded their answer to embrace a network of relationships:

Wife/patient: *I've had a lot of friends that are praying for me, and it makes me feel good to know that these people out there are all trying to support me . . . and that they're all rooting for me.*

Another facet of the PC-ACP focuses on what it means to the patient to live well. This is designed to begin the discussion about key elements underpinning quality of life from their perspective. Again, all of

the patients focused on family and meaningful activities with close friends. One participant stated it this way:

Wife/patient: *Living well means for me to be with my family and kids and see them growing up and getting married and having children — my grandchildren.*

Another patient described the importance of continuing to care for his family as part of living well. Just as he drew strength from his wife, she drew strength from him:

Researcher: *I'm also hearing you say [that] part of living well for you at this time includes not only visiting your family but caring for them and to some degree protecting them.*

Husband/patient: *Definitely.*

Wife: *That's what he's doing, making it easy for everyone in whatever ways he can . . . If he weren't of the strength and calmness that he has been, I'd be a lot worse off. Like I said, he's trying to make it easy on me.*

The interactional process was slightly different when the dyad was husband and wife versus parent and child. Well spouses tended to take a more active part in the process than children, and husbands in particular often responded to questions by voicing their thoughts, values, and beliefs regarding their own situation. This led to a dual focus on the spousal partners and sometimes a dual planning process. Children tended to engage in the process by maintaining the focus on the ill parent. While the children offered ideas and posed questions, these were about the parent and not themselves. Both well spouses and children were active in clarifying the perspective of the ill person, either by asking questions or offering a counterpoint that stimulated discussion and reflection. One of the explicit goals of the ill participants was to avoid burdening their family. The predominant goal for all was to avoid unnecessary suffering for the ill person, especially as the end of life approached. There was extensive discussion within all dyads about the importance of good pain management. An intimate relational process, with family at the centre, characterized not only the narrative phase of the intervention but also the decision-making phase, which is discussed below.

Decision-Making Around End-of-Life Preferences

The articulation of end-of-life preferences revolved around five explicit health-related scenarios that may realistically be faced by someone with advanced lung cancer. Discussion focused on the benefits and burdens of treatment; the probability of these benefits and burdens manifesting; and the patient's values, beliefs, and views regarding quality of life. While the intervention focused on burden for the patient, the participants often

shifted the focus to include the burden on the family:

Husband/patient: *And the burden you're putting on your family, too. I mean, I would not, with all sincerity, want my wife to come and spend hours in a hospital watching me with tubes going every which way. That's not quality of life for her and it's not quality of life for me.*

Again, family members were very active in the process. It was not a matter of quietly observing and listening to the patients think through their preferences. The process showed deep relational engagement. The following excerpt pertains to a scenario of permanent cognitive impairment and a good chance of survival:

Researcher: *So, not knowing who you are or whom you are with . . .*

Wife/patient: *Ah, forget it.*

Husband: *Yeah.*

Researcher: *So which would be your choice?*

Husband: *That would be number two — stop all efforts to prolong my life.*

Researcher [to wife/patient]: *That's what you're saying?*

Wife/patient: *Mm hmm. We are real clear on that.*

Husband: *Exactly.*

Note the wife's use of the word "we," which so beautifully captures the joint decision-making and, in effect, joint planning.

Sometimes, family members sought clarification of the patient's position, assisted in the negotiation of meaning, and influenced a shift in perspective, as can be seen in the following exchange. Here, the researcher is trying to determine what the patient would consider a poor chance of survival:

Researcher: *We were wondering [about] low chance of survival for you, what percentage would that be?*

Husband/patient: *Five percent.*

Wife: *I guess.*

Researcher: *Would that be in keeping with what you would define as low, or would another number be appropriate?*

Husband/patient: *I think we probably would raise that to a quarter [25] percent. I say 50 percent is probably too high, because if you have a 50/50 chance, well, then, I'd try to survive . . . but below 50 percent . . .*

Wife: *You think so, Dad? Oh, I wouldn't give up that soon.*

Husband/patient: *Well, I don't know . . .*

Wife: *Well, 50 percent seems pretty high to me; five percent sounds okay to me.*

Researcher: *So for you [wife], five percent would sound right for you, but what we are hearing [husband] say is that low for him would be—*

Husband/patient: *—about five percent . . . My brother, he had 6 months to live, but he lived for 2 years . . . He got longer [than we expected].*

It was not uncommon for patient preferences to shift after discussion and reflection.

In one family, the husband was dominant throughout the interview. The following excerpt pertains to the scenario of prolonged hospitalization with a poor chance of survival. One of the strongest themes for this family was the importance of hope:

Husband: *As long as there's hope.*

Wife/patient: *As long as there's hope, even [with] five percent there's still hope.*

Husband: *Okay, if you were going to have a prolonged hospital stay, that doesn't mean permanent hospital stay — so then there's hope for survival. If there's no hope . . . like, once hope is gone . . .*

Researcher: *Here, they're saying hope for survival is really low, less than five percent.*

Husband: *I'd have to say just let her go.*

Wife/patient: *Yes, I'd say that.*

In the second scenario, that of functional impairment, the need for 24-hour nursing care, and a good chance of survival, the patient was initially uncertain about her preference. The husband led the discussion and his wife soon arrived at her choice, which she was able to explain based on the case of someone who managed well with functional impairment:

Wife/patient: *I don't know.*

Husband: *Well, you know, okay, if you can't walk, you can't talk . . . I've known a lot of people who've spent a lot of years in a wheelchair, and . . . quality of life is still there for them.*

Researcher: *I guess what we're trying to determine is, is that acceptable to you [wife/patient]?*

Wife/patient: *I think so — like, there are other ways of communicating.*

Husband: *And there are other ways of being mobile.*

Wife/patient: *Yeah.*

Husband: *Yeah, because anything less [than complete paralysis] and you can train yourself to be able to function.*

Wife/patient: *Right. You see a lot of people out there with different impairments. We have one guy [here] that has had his leg off. He's young, and, you know, he can get around better than most people, on his one leg. He's a fighter.*

This woman chose to continue all treatment to prolong life unless the functional impairment was complete paralysis. Like this participant, many patients framed their preferences in light of experiences with others, usually family members or close friends, at end of life where treatment delayed death and prolonged suffering.

In terms of decision-making should one be unable to speak for oneself, most patients wanted their family member to use his or her judgement rather than strictly follow their stated preferences. Most were committed to involving additional family members, at a minimum by providing them with a copy of the statement of preferences or via ongoing conversations. One patient got part way through decision-making and stopped, as he wanted to work through his preferences with input from his adult children. Another patient agreed to stop the discussion of scenarios at the request of his wife, who was overwhelmed and worried that her emotions would not help either of them; they agreed that it was important to have the conversation but wanted to have it privately at a later time.

For those families who participated in a follow-up interview, none had involved their health professionals in ACP in any way, despite being asked to do so. It was clear that they viewed ACP as a family affair and felt safe knowing that their wishes were clearly understood by a trusted loved one who could speak on their behalf.

All participants evaluated the intervention as difficult but helpful:

Daughter: *Well, I have to say that that interview was really, really hard for me . . . it was really, really tough, but I feel, and I know you [mother] felt, that it opened a lot of doors that I couldn't hardly bring myself to talk to Mom about. It was in the back of my mind, thinking, well, we have to talk about this . . . should I do it now or should I wait until I see how the treatment is going?*

Mother/patient: *We've come closer . . . it opened the door for us.*

This family continued the conversation over time, and at follow-up the patient reported that "everything is in order" and her daughter stated, "We are prepared." Several participants noted that the conversation brought an enhanced sense of closeness.

One participant who, based on an experience with her mother, was determined not to accept life support, had completed a living will some years prior to the intervention. She and her daughter evaluated the PC-ACP this way:

Mother/patient: *I really thought that going to my lawyer made it pretty clear how I wanted things, but there were other things that I just didn't think about.*

Daughter: *It certainly clarified things for me, because the scenario is different. You're not really aware of all the symptoms that can happen and all the decisions you'll have to make. I think this really clarifies exactly how Mum feels on all of them . . . it will help.*

Follow-up with this family occurred after the mother's death and was the only evaluation of the influence of the intervention at end of life:

Daughter: *It sure helped us a lot, especially when she was in hospice and asleep, or unconscious or whatever you call it . . . There was no question. We all knew exactly what Mum wanted. We might have wanted to prolong it for ourselves, but we knew she had made her wishes so clear that there was no question about it . . . The specific examples [we talked about] made our job so much easier. The living will . . . wouldn't have been enough to help us.*

It is clear from the family perspective that ACP is an endeavour that is deeply embedded in intimate family relationships.

Discussion

The ACP process we observed, rather than being a process for preparing a substitute decision-maker to speak for oneself and direct health care at a time when one is incapacitated, is one where people come to a shared understanding of their own preferences in conversation with loved ones. Our findings are in alignment with those of others (Martin et al., 1999; Singer et al., 1998) who found that, from the patient perspective, the primary goals of ACP are psychosocial: avoiding prolongation of death, strengthening relationships, achieving a sense of control, minimizing burden, and managing pain. Most patients wanted their family members to use their own judgement when making end-of-life decisions, rather than strictly relying on their stated preferences for care (see also Collins et al., 2006; Puchalski et al., 2000). This finding calls into question the view that ACP is successful only when a family member's decisions mirror those of the patient. Like Gardner and Kramer's (2009) participants, the patients and family members in this study had slightly different concerns, the common thread being relational attention to the well-being of the other, aimed at reducing burden and suffering.

The emphasis on ACP as a vehicle for the expression of an individualistic notion of autonomy is not in keeping with how the process is lived. While there is broad agreement that autonomy is central to bioethics, there is also recognition that the concept has limitations in practice (Bergum & Dossetor, 2005; Christman, 2004; Mackenzie & Stoljar, 2000; Sherwin, 1998). A critique of autonomy is beyond the scope of this article; readers seeking a more fulsome discussion are

referred to feminist scholars who have developed a compelling argument that autonomy be re-conceptualized in relational terms (Mackenzie & Stoljar, 2000; Sherwin, 1998). The fundamental notion here is that humans are essentially social beings, embedded in and shaped by intimate relationships, which are characterized by interdependence, and that the development as well as the exercise of autonomy is not solely an individual enterprise (Ho, 2008; Mackenzie & Stoljar, 2000; Sherwin, 1998). Interdependence encompasses the idea that we are both dependent and independent, that what we do affects others and what they do affects us (Bergum & Dossetor, 2005). The patients who participated in this study were mindful not only that they needed the support of their family to have their preferences for care at end of life honoured, but also that their preferences had consequences for family. All of the participants were vulnerable, fragile, and at risk of isolation as they worried about how to engage in a meaningful way that would not “spoil the moments” left to them. When patients adhere to an individualistic approach to end-of-life decision-making that does not acknowledge dependence on family, their demands may override the needs of caregivers and leave them inadequately prepared (Sahlberg-Blom et al., 2000). Thus, an approach to ACP that rests on individualistic conceptions of autonomy with requirements for people to make decisions separate from family carries a high risk for increasing vulnerability for all, while compromising dignity and well-being (Ho, 2006; Sherwin, 1998). As Ho (2008) argues, against the backdrop of often impersonal, fragmented institutional health care “it seems that family involvement and patients’ relational identity are more important than ever in preserving or restoring patients’ autonomous agency” (p. 131). As the participants in this study demonstrated, autonomy is lived as a relational experience (Bergum & Dossetor, 2005).

This was a small study with a narrow focus. Nevertheless, the findings suggest the need for a shift in the ethical underpinnings of ACP. An approach to ACP that is informed by relational autonomy has the potential to serve patients and families well. This approach does not deny that autonomy resides in individuals, but it supports a process that “is both deeper and more complicated than the traditional conception acknowledges” (Sherwin, 1998, p. 44).

Implications for Practice and Research

Like the patients in the study by Singer and colleagues (1998), the participants in this study did not involve health professionals in ACP. What does this mean for our participation in the process? Current recommendations focus on the development of specialized facilitation skills (Atkins, 2006) and of supportive clinician-patient relationships (Entwistle, Carter,

Cribb, & McCaffery, 2010) to enhance autonomy. Practice recommendations often position the health professional as the “significant other” in the process. Based on the findings of this study, nurses can be helpful to families by viewing family broadly as those individuals who are important to the ill person, approaching ACP from a relational perspective, developing the skills necessary to facilitate family conversations, providing accurate information regarding likely health complications during illness progression, following the family’s lead with regard to pacing, and setting aside the notion that we are central characters in the relational process. Family is at the heart of ACP.

Research is needed to determine the most effective way to implement a relational autonomy approach to ACP and to evaluate whether the outcomes of such an approach support the psychosocial goals of families and the outcomes of “good” living and dying at end of life. Kolarik, Arnold, Fischer, and Tulsy (2002) point out that determining the effectiveness of ACP has proven difficult. They state that the main problem is lack of clear and comprehensive goals. I argue that the greatest barrier is an ethical foundation that orients us to goals that are not in alignment with the relational process.

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