

The Family as Window onto the World of the Patient: Involving Patients and Families in the Decision-Making Process

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L'approche selon laquelle les membres d'une famille peuvent défendre les droits d'un patient ou agir en son nom lorsque celui-ci n'est pas en mesure d'exprimer ses volontés n'est pas remis en question. Cependant, les méthodes utilisées pour favoriser la participation des membres d'une famille dans le processus décisionnel font encore l'objet de débats. Les décisions peuvent être complexes et l'environnement dans lequel elles sont prises peut s'avérer chaotique, alors que l'approche décisionnelle des cliniciens peut souvent être perçue comme froide. Les familles sont aux prises avec le lourd fardeau émotif que leur confère leur rôle et les cliniciens s'efforcent à traduire des données complexes en des termes compréhensibles, explicites et concrets. Il faut donc examiner la pratique clinique afin d'identifier les approches les plus appropriées quant à la participation des membres d'une famille, autant sur le plan philosophique que sur le plan pratique. L'article explore les multiples facettes du rôle décisionnel conféré à une personne représentant un patient et suggère une réorientation des modèles actuels de la relation professionnel-délégué.

The need to involve family members as patient advocates and as surrogates when patients are unable to speak for themselves is not an issue. What continues to be debated are the methods for involving family members in the decision-making process. Such decisions can be complex and the environment in which they are made can be chaotic, while clinicians' approach to decision-making is often seen as insensitive. Families struggle with the emotional burden of their role and clinicians struggle to translate complex information into comprehensible, meaningful, and practical language. There is a need to examine clinical practice to determine which approaches to involving family members are preferable from a philosophical as well as a practical point of view. The paper explores the many facets of the surrogate decision-making role and suggests a reorientation of current models of the professional-surrogate relationship.

During the war, I met my wife. She and I were the only ones left of our families — can you imagine, no one left but us? Now, 53 years later, I look at her face in that bed and I see all we have been through, the courage that has sustained her all her life, the wonderful mother she has been, and I am reliving our life together. We are so bound together that I know that once she is gone I will not be far behind. Our souls would cry for each other.

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At some point in the not-too-distant future, the clinicians working with this man and his wife will approach him and begin to discuss treatment options, perhaps even broaching the subject of withdrawal of therapy. The patient, frail and sedated, will be unable to participate in the discussion. The team will turn to her husband, frail and grieving, and ask him to help them reach a decision. Multiple factors, such as age, stage of illness, ability to comprehend, patient and family history, and the sensitivity with which the subject is broached, may affect the husband's ability to respond and work with the team to ensure that the treatment goals and decisions reflect the values and beliefs of the patient.

The role of family members as surrogates continues to be discussed, debated, and challenged. The literature to date does not reflect consensus on the role of the family and on the most effective methods for including family members as surrogates.

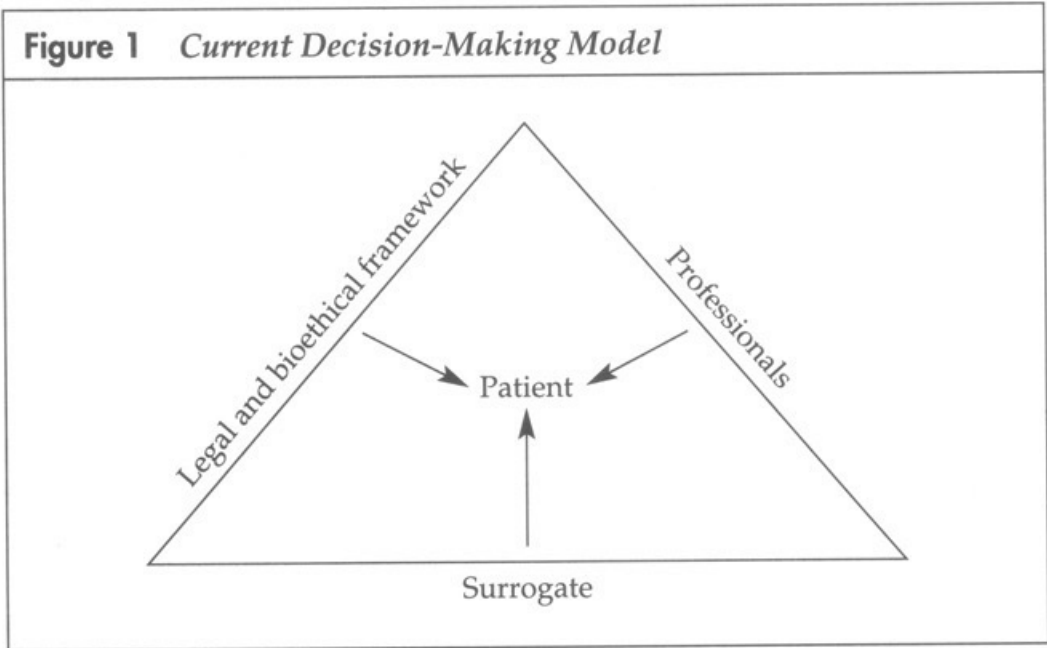
Clinical interventions to include patients and families in end-of-life decision-making will be enhanced if they are based on a thorough understanding of the debates and challenges. Comprehensive, compassionate interventions must be founded on the many issues that face family surrogates and the clinicians who seek to assist them in that role.

The purpose of this article is to examine the role of family members as surrogate decision-makers. The discussion begins with a brief review of the current legal and bioethical standards for decision-making. While most patients assume that their family members will be able to speak on their behalf if they become incompetent or incapacitated, the research findings are discouraging. And while most health professionals support a role for families in patient advocacy, they have difficulty articulating the means by which the family might be included in the many facets of care. The discussion then moves on to the need for a reorientation of thinking towards a concept of the patient and family as a single entity and the many challenges that such a concept poses. The discussion concludes with an analysis of methods for enhancing the relationship between health professionals and family members. The literature suggests that a shared decision-making framework can lead to the kind of partnership that will promote the well-being of the whole family.

A Framework Ready to Be Challenged

The process of decision-making in end-of-life situations can be seen as a triangle, its three sides meeting but not necessarily interconnecting (see Figure 1). One side represents a legal and bioethical framework that has championed the well-being and autonomy of the incompetent/inca-

pacitated patient using the substituted decision-making standard as a means of preserving autonomy. Another side represents clinicians who are aware that their work with patients should include family members but have little training and sensitivity in this regard. A third side represents the surrogate decision-makers who are being asked to take on more and more responsibility for decision-making but are often isolated from the process until called upon to make a "quick and dirty" final decision.



Often, professionals and patients or surrogates work in parallel or are even at odds with each other. Frequently as well, insufficient time and energy are spent in making sure that information shared has been understood, and in working with the surrogate to orient the goals of treatment towards the values and beliefs of the patient. Discussions in a time of crisis are fraught with tension and can end with both professionals and surrogates wondering if they have done the "right thing." These factors leave the patient somewhat isolated from the process and, sometimes, from the decisions being made on his or her behalf. Each of the sides of the triangle will now be discussed and a reorientation of the process suggested.

Legal and Bioethical Standards of Decision-Making

The first side of the triangle represents the bioethical and legal frameworks on which clinical decision-making rests. The patient who is ren-

dered incompetent or incapacitated by an illness or its treatment, while remaining a person worthy of respect, will be unable to speak on his or her behalf. Clinicians must continue to seek to discern the patient's wishes, based on their values and beliefs. The treating team will call on the identified surrogate to assist in making decisions on the patient's behalf. If the patient has prepared an advance directive, the team and the surrogate will be guided by the information within. If the patient has not done so, treatment decisions will still have to be made.

It is part of Canadian culture to expect that if one is unable to make decisions due to incompetence or incapacity, one's family members will speak on one's behalf. Family is usually defined as including those bound not only by blood but also by relationship, interdependence, fidelity, or long-term commitment (Blustein, 1993; Hardwig, 1990; Jecker, 1990; Nelson & Nelson, 1995; Wright, Watson, & Bell, 1996). What is not covered in law, clinical practice, or social upbringing is how one actually goes about fulfilling the role of surrogate decision-maker.

Current legal jurisprudence and bioethics literature suggest that a surrogate be asked to make decisions using a Substitute Decision-maker Standard, an approach based on knowledge of the values and belief systems of the incompetent patient. Surrogates using this "substituted judgement" approach are expected to "reach that decision which the incompetent patient would have chosen had he or she been competent" (Freedman, 1999, p. 79).

The Substitute Decision-maker Standard assumes that family members and other substitute decision-makers have intimate knowledge of the values and beliefs of the patient and an innate ability to articulate his or her express wishes (Buchanan & Brock, 1989). It appears to be based on a belief that the surrogate's insights into the character and nature of the patient will be sufficient to preserve the notion of self-determination. However, some authors argue that it is impossible to put oneself into the shoes, let alone the mind, of another person without the benefit of an advance directive (Buchanan & Brock; Suhl, Simons, Reedy, & Garrick, 1994).

If no explicit wishes have been expressed, or if the patient's wishes are not known, the Best Interest Standard may be the most logical and feasible choice for surrogates and clinicians. Buchanan and Brock (1989) note the significance of the word "best" here, as with this method the decision-maker endeavours to determine the most appropriate, acceptable, and important interest of the patient, then acts accordingly. The patient's "best interest" is a mechanism for protecting his or her auton-

omy. The Best Interest Standard differs from the Substitute Decision-maker Standard in that the surrogate does not act based on the patient's known, or even assumed, wishes, but rather attempts to determine "the medical course of action most likely to maximally contribute to the patient's welfare" (Freedman, 1999, p. 79).

The Substitute Decision-maker Standard places an enormous burden on the surrogate. Some authors express concern about the many pressures that surrogates must endure: financial burden, cultural and religious conflict, emotional stress, fatigue, power struggles with professionals, and difficulty understanding complex medical treatments, medical technology, or the medical system itself (Ellman, 1990; Freedman, 1999; Hardwig, 1990; Keyserlingk, 1997; Pinch & Spielman, 1990). The intimacy of the family unit also suggests that the illness of one of its members becomes a shared experience, as roles, responsibilities, and support networks shift and change. These issues, together with clinicians' tendency to overlook the impact on the surrogate, make it difficult to understand how substitute decision-making can benefit the patient without placing an overwhelming burden on the surrogate. In the face of such difficulties, how can patient-centred decisions be assured?

Professionals Working With Surrogates

The second side of the triangle represents the dilemmas that face clinicians as they struggle to reach decisions on behalf of their patients. Without personal knowledge of the patient's values and beliefs, and often with little knowledge of the relationship between the surrogate and the patient, a clinician may be reluctant to accept evidence, whether direct or indirect, of the patient's express wishes. The competing roles of professional as patient advocate and family member as patient advocate may lead the clinician to demand a very high standard of evidence. The focus in health-care education on the absolutes of evidence-based decision-making may further lead a clinician to consider any data, even written directives, that have not been collected by the clinician as subject to bias and potential conflict of interest.

While there is legal and bioethical consensus that surrogates must be included in decision-making if patients are unable to speak for themselves, there is little consensus on the nature of the relationship between the professional and the surrogate as a representative of the patient. The debate on this subject is outlined below.

Hardwig (1990) expresses the opinion — challenged by other authors in the bioethics field — that it is naive to view the family as defender of the patient's autonomy, that family members, by virtue of their intimacy and interconnectedness with the patient, have interests of their own that should be factored into any decision. He argues that the health-care system has focused solely on the needs of the patient and largely ignored the implications for and burden on the family. While the patient merits special attention, Hardwig argues, the family is highly implicated in many of the decisions that are made on the patient's behalf. He suggests that any new medical ethic should be based on a principle of equality whereby "the interests of the patients and family members are morally to be weighed equally; medical and non-medical interests of the same magnitude deserve equal consideration in making treatment decisions" (p. 7).

This type of reasoning can be challenged on many counts. In our present health-care system, with its shortage of both human and material resources, the ability of caregivers to develop a relationship with the patient, let alone a number of family members, is being eroded, making the chances of "knowing" even more remote.

Hardwig's most serious criticism of current thinking is that it does not adequately reflect the prevailing collective form of decision-making. Patient autonomy viewed purely as self-determination should be reserved for decisions that affect only the patient. He suggests that an appropriate way of ensuring a more equitable process would be to avoid "asking a family member to pretend that her interests are somehow irrelevant. Rather, the best safeguard would be candidly to admit the moral relevance of the interests of other members of the family and then to support the family through the excruciating process of trying to reach a decision that is fair to all concerned" (1990, p. 10).

While clinical work with families as surrogates is clearly moving in the direction of a larger decision-making role for families, Nelson (1992), as a counterpoint to the above argument, suggests that while the patient should be obliged to consider the impact of his or her decision on the family, and the family should be intimately involved in decision-making, the process can become cumbersome, particularly if the family cannot find a voice of consensus (p. 11).

Blustein (1993), in a critique of Hardwig's (1990) ideas, agrees that the current perspective of the family needs modification but does not support complete equalization of their rights. He is of the view that a communitarian conception of the patient and family, in which they are

interrelated and interdependent, better reflects the reality. In a communitarian approach, the patient would remain the "decisional locus of control," with the family playing a more familiar mentor, facilitator, or supporting role. The emphasis would be not on fairness and autonomy but on decision-making within the frame of a "community," where mutual respect and love ensure that the individual is protected within his or her own circle.

Blustein (1993) acknowledges that the picture of family he describes may be somewhat idealistic: "Even in extremely close families, patients may have different priorities from their loved ones and assess life choices in disparate ways, and these differences may surface in disagreements about how and even whether patients should be treated" (p. 11). Such differences could be mitigated, he suggests, if the role of the health-care team were expanded to include the facilitation of discussions between patient and family.

The standard interpretation of surrogate decision-making as little more than a courtesy to the family may be the result of ignorance on the part of clinicians who have been socialized into a "patient autonomy" approach. Clinicians are often reluctant to speculate about the outcome of a condition for fear of being wrong and losing the family's respect, or causing them to lose hope and their ability to cope. Families, on the other hand, often seek certainty or guarantees on which to base their decisions, yet rarely can a clinician predict the outcome with 100% accuracy. Because of these two layers of fear, there may be only an illusion of truth in conversations between clinicians and families, with pertinent information sitting under the surface.

A reorientation of professional thinking away from a patient-autonomy approach and towards a patient-centred approach may be necessary. In such an approach, the patient would be considered within the context of his or her social group of intimates. As part of the patient's development, well-being, and, ultimately, death experience, such intimates cannot be excluded or marginalized. This approach may be facilitated by dialogue that focuses on the patient, but only in the context of his or her lived experience, which includes the circle of intimates. Placement of the patient within a circle of intimates does not suggest an equalization of the rights or considerations of all those within the circle. Blustein's (1993) criticisms of the notion of equalization of rights are valid: as with most family situations, at times the needs or concerns of the patient will take precedence, while at other times these will have to be balanced against the needs and values of the group.

Surrogates Struggling With Their Role

The third side of the triangle encompasses the numerous factors that make up the role of surrogate. Many authors have discussed the practical challenges faced by surrogates. Despite the concerns expressed by both surrogates and professionals, the patient's family is still considered the prime decision-maker. However, it is not uncommon for families to be torn by the desire to hold on to their loved one and the desire to end the suffering. These overwhelming feelings can make it difficult for them to reach any decision for fear of making the wrong one and causing more suffering.

Despite research evidence showing that only a small percentage of persons rendered incompetent or incapacitated have actually talked to their family members about making decisions for them (Sawchuk & Ross-Kerr, 2000), the assumption persists that family members, spouses, and in some cases physicians will "know" how to speak on patients' behalf and will accurately reflect their wishes. Several studies have found that faith in the ability of a surrogate to do so may be misguided.

Research has shown that there is discrepancy between the choices of patients and their surrogates, on the one hand, and the choices of physicians, on the other, in the same cases. One study found that physicians were more likely than family members to withhold care that the patient would have wanted (Seckler, Meier, Mulvihill, & Cammer Paris, 1991). This study and others (Hare, Pratt, & Nelson, 1992) found that while family members were more accurate than professionals in interpreting patients' wishes, there was still a significant difference between the responses of surrogates and those of patients.

Discrepancies in congruence have been attributed to patient fear of burdening or prolonging the suffering of family members and family fear of seeing the patient in pain (Hare et al., 1992), and to types of treatment or stages of illness (Sulmasy et al., 1998). It has been found that intimacy or longevity of relationships does not necessarily increase congruency (Pearlman, Uhlman, & Jecker, 1992). It has also been found that, in the face of terminal illness, demographics such as age, ethnicity, or religion, relationship of the patient to the surrogate, the presence of an advance directive, or surrogate's perceived level of comprehension of patient's wishes do not affect congruence between patient and surrogate. Factors that have been found to increase the congruency and accuracy of decisions include a higher level of education, previous conversations with the patient, life expectancy of less than 10 years, no

personal experience (on the part of the surrogate) with a ventilator, and not attending church (Sulmasy et al., p. 624).

Sawchuk and Ross-Kerr (2000) found that very few patients had shared their preference for resuscitation with their family (16%) or their doctor (7%). This one factor appears to be key in much of the available research. Face-to-face communication seems to be the essential element in a family's ability to accurately reflect the wishes of the patient. Even the existence of an advance directive is not useful for the surrogate, it has been found, if the surrogate is unaware of it or if there has been no discussion of its contents. This finding may be related to the fact that advance directives are often broad, vague, and unspecific. For this reason families may not find them helpful.

It is obvious, then, that membership in the patient's intimate circle does not guarantee that a person will have sufficient knowledge to fulfil the role of surrogate. In addition, the decision-making process will have to be reoriented, to allow the surrogate to work with the team in determining patient-centred treatment goals, particularly if discussions have not been held with the patient. A new focus with patients, encouraging discussion with, and inclusion of, surrogates in health-care decision-making throughout the course of an illness trajectory, may also be necessary.

Reorienting the Decision-Making Process

As indicated in the literature and in the most widely recognized decision-making standards, it is not always easy for the clinician to know how to involve the surrogate, family or otherwise, in the decision-making process. The reluctance of both professionals and surrogates to face what may be a very unpleasant reality — a vegetative state, a severely compromised life, or the prospect of a difficult death — could mean that these issues are rarely even up for discussion. There may be genuine reluctance on the part of both parties to use the language of future outcomes or to focus on disability for fear of dismissing or being disrespectful to the patient — perhaps complicated by a fear of failing in one's obligation, whether professional or familial, to the patient (Freedman, 1999).

Despite the concerns, it is a reality that clinicians, the courts, and most importantly patients want and expect family members to become involved in the decision-making process. Recognition of the need for patient surrogates and the need to ease the decision-making burden has prompted a search for solutions.

Although advance directives are seen as one solution to the problem of inaccuracy and incongruency, the literature shows that few Canadians have completed such directives (11%) (Sawchuk & Ross-Kerr, 2000; Singer, Choudry, Armstrong, Meslin, & Lowy, 1995) or have had an opportunity to follow them (Gordon & Shade, 1999; Sawchuk & Ross-Kerr), while one American study found little follow-through on intention to discuss and document advance directives (Hare et al., 1992).

Slomka (1992) suggests a process of working towards a mutual understanding of both medical problems and patient preferences. While some might argue that this is in fact the current practice amongst physicians, nurses, and family members, Slomka favours a scenario of shared meanings of options and potential outcomes over a scenario in which the family has input but bears little responsibility for the results. Research consistently shows that patients are not discussing end-of-life issues with their families. If medical residents and nurses were educated in the advantages of raising these issues early on, and were provided with the skills to approach the subject sensitively, then patients might be encouraged to take the next step. Urging patients to talk to family members about end-of-life issues will not become common practice until the treating teams have developed more ease with talking to patients about them.

Freedman (1992, 1995), in his writings on competence and informed consent, expands on the concept of patient-family discussions. He suggests a reorientation away from the current focus on such legal concepts as risk, benefit, burden, and competence, and towards a broader dialogue that would include an examination of the patient's values and beliefs as well as the practicalities of the disease and the treatment options. Such a dialogue would promote an understanding of not only the illness and its impact, but also the consequences of the different treatment options for the well-being and life goals of the patient and family. Many clinicians lack the skills to participate in, much less lead, such discussions.

The idea of "sharing" information is a particularly interesting one. Sharing suggests a give and take of not only information but also feelings, opinions, and ideas. This is not an approach that most clinicians have been trained in. In general, in fact, clinicians have been led to believe that it is not only unnecessary but wrong to share too much information with patients, as they will not be able to understand it.

I began this article by identifying three sides of a discussion triangle — a bioethical framework of substituted decision-maker, clinicians

with a need to alter their approach and philosophy, and a surrogate — usually someone who is playing the role for the first time. The patient seems isolated from the process when there is little interaction amongst the various players (see Figure 1). What if one were to alter the triangle and make it a circle? If one chose to work with the patient and surrogate as a single entity and place them at the centre, and make the purpose of the discussion patient-centred treatment goals and decisions, how would this affect the methods and the cause of preserving the patient's well-being and self-determination?

The President's Commission (1982) described an historical shift over the preceding two decades in philosophy towards the patient, from a philosophy of "medical paternalism" to one of "patient sovereignty." In medical paternalism, the physician is the dominant figure in the relationship, with both the right and the responsibility to make decisions in the best interest of the patient. In patient sovereignty, on the other hand, the patient is assigned full responsibility for and control over all treatment decisions, with the practitioner acting as the patient's servant, sharing information and knowledge but exerting no influence over the decisions of the patient (p. 36). Neither of these philosophies — polar opposites in both orientation and outcome — has produced a satisfactory relationship between the patient and the practitioner.

What is needed is a philosophy in which the decision-making process is at the centre of the continuum, midway between medical paternalism and patient sovereignty. The reality is that there is little understanding of what constitutes "shared" decision-making. Professionals and surrogates, as representatives of the patient, enter into the decision-making process as bearers of two different but equally important bodies of knowledge. The professional brings information on the patient's health/illness status, while the patient/surrogate brings information on the patient's values and beliefs, which are pivotal to discussions about the impact and consequences of treatment outcomes and the establishment of patient-centred goals.

Several studies have dissected end-of-life decision-making in an attempt to find ways of facilitating the process through shared decision-making. In two recent articles, Charles, Gafni, and Whelan (1997, 1999) break down the process of shared decision-making into three distinct steps: information exchange, deliberation on treatment options, and selection of a treatment option. In a shared process, information exchange is a two-way flow between participants (Charles et al., 1999).

The second step, deliberation on treatment options, is what sets a shared process apart. This step is characterized by an expectation of

exchange, of sharing preferences, both medical and personal, of interacting on the choice of a treatment option, and of the consequences of decisions for all parties. Frequently it is at this point, or even earlier, that the family begins to share in decision-making and the patient decides who will participate in the process (Charles et al., 1997, p. 687). Effective deliberation calls for an environment of trust such that the patient and family members are able to participate freely and feel that their concerns, questions, and recommendations are a legitimate and valuable part of the process. A key factor at this stage is the physician's ability to share in the thinking processes behind the options chosen and make appropriate recommendations without unduly influencing the decision-making process.

The final step in a shared decision-making process is the actual choice and implementation of a plan for current and possibly future care. The deliberation process entails a shared decision with specific goals that all parties are comfortable with and, in fact, are invested in (Charles et al., 1999, p. 658).

The concept of deliberation merits further examination, as it is a key element in the process of shared decision-making. Clinicians need to know what elements are most important to the establishment of patient-centred decisions. There are few studies examining the process of surrogate decision-making, yet such research can greatly enhance the ability of caregivers to work with surrogates in a meaningful way.

Swigart, Lidz, Butterworth, and Arnold (1996) began the arduous task of identifying the role of the surrogate decision-maker by interviewing family members of 16 patients as they struggled with "letting go," or "becoming willing to forgo life support for their relative" (p. 484). They describe three distinct steps in a family's process of "coming to terms": (1) understanding and reframing the critical illness, (2) reviewing and revising the perceived life story of the patient, and (3) maintaining family roles and relationships (p. 485). Each of these steps involves interactions with professionals and with other family members. The first step, which is key to the family's ability to take on a surrogate role, involves seeking comprehensible information, understanding the course of the illness, and developing a relationship of trust with the caregiving team, especially the patient's physician. Swigart et al. describe this configuration of processes as "believing, ordering and integrating information received from the external environment" (p. 487). The second step is a life review focused on "the meaning and the course of the patient's life and...what the patient would have valued in this situation" (p. 488). The final step is one of "fulfilling of roles of

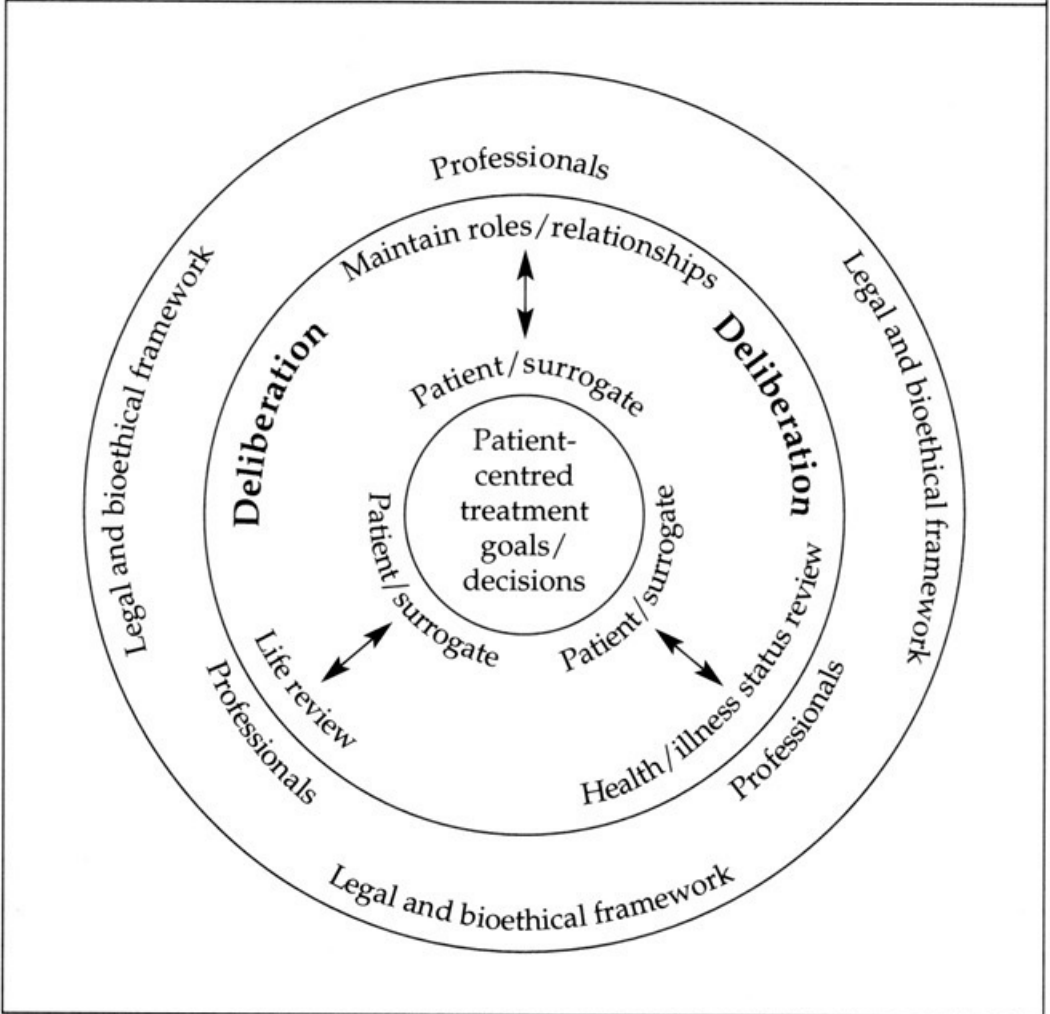
responsible and caring family members, and attending to how the situation could affect family relationships thereafter" (p. 489). Because human beings live in reciprocal relationships within social networks, families both influence and are influenced by an illness experience (Wright et al., 1996). Family members are often struggling with their role as advocate or decision-maker, their emotional attachment to the patient, and their own responses to the disease and the ever-present illness experience (Swigart et al.; Wright et al.). For most families, there is a seeking of mutual agreement on family issues, a seeking of consensus on decisions, and a concern for others in the family network (Swigart et al., p. 489). For some, consensus-seeking is a way of sharing the burden or blame for decisions taken.

Within the discussion of deliberation, the elements described by Swigart et al. (1996) might be considered essential to the discovery of who the patient is and how the proposed treatments will "fit" with the patient's values and beliefs and ease the decision-making burden. Since the processes of understanding and reframing the illness, reviewing and revising the patient's life story, and maintaining family roles and relationships call for interaction between family members and professionals, they are components of deliberation (see Figure 2). Charles et al. (1997, 1999) maintain that professionals must become actively involved in the process of deliberation. In light of the elements identified by Swigart et al., active engagement must include interpretation on the part of both the professional and the surrogate. According to Wright et al. (1996), family members are often so focused on the "description" of the illness — symptoms, tests, diagnosis, drugs, and so on — that they are unable to, or are not encouraged to, move on to a discussion of the illness "experience" for the patient (p. 61). This can also be a factor in the discussions between family and professionals as outlined above. If one or both parties to the discussion are unable to "see or know" the current or projected future reality for the patient, it will be difficult for them to have a legitimate conversation about ongoing care. Interpretation of the sort described will require a relationship of trust, as defined by Charles et al. (1997). The relationship itself is as important as the information to be shared and deliberated on.

Practice Changes to Enhance Shared Decision-Making

One important factor in the development of the shared decision-making approach is that the chaotic, sterile, disjointed clinical practice environment will have to be altered. As the "walk-in clinic" model of care, in which one rarely sees the same physician or nurse twice, becomes more

Figure 2 *Patient-Centred Deliberation Model*



and more prevalent, the difficulty of having connected, meaningful patient/surrogate-focused deliberations will only increase. The changing-physician phenomenon, while the norm for most wards and clinics, is not reflective of the caregiving team. With the exception of the physicians, the professionals on health-care teams do not change, possess the necessary professional skills, and are already providing support, care, and advice to patients and surrogates.

One way of resolving the changing-physician issue would be to establish small interdisciplinary teams to work with specific patient populations, such as the aged or those with a chronic or a terminal illness, over time. Keyserlingk (1997) proposes a more systematic team approach that would lift the burden of responsibility for one professional to provide the type of support and leadership described above. He argues that medical institutions consistently under-use and,

perhaps, under-value the caregiving team. Both nurses and physicians feel they are patient advocates, but within the functioning of the team they often work in parallel rather than in synchronicity. Team synchronicity facilitates the sharing of information, skills, and perspectives and prevents duplication of work with patients and families. This type of work requires an atmosphere of trust among professionals, which, Keyserlingk argues, has not yet developed nor been fostered by institutions, to the detriment of both patients and professionals (p. 130).

Members of a team would need to be trained together and to be committed to the patient/surrogate-centred approach. Planning with the patient/surrogate would include deliberations as described above, always with both short-term and long-term consequences in mind.

While psychosocial assessment and interventions with patients and families has long been a foundational component of nursing education programs, and while the expectation that an intervention will benefit both patient and family is recognized in the nursing code, the nurse's role as a patient and family advocate has been underdeveloped.

Although psychosocial intervention has not historically been a focus in medical curricula, over the past decade communications skills and an appreciation of socio-economic, ethnic, and cultural influences have become essential for the physician. While efforts are being made to provide such training for medical students, in reality it is still often seen as a necessary evil or as an add-on, as opposed to an essential component of practice. Medical students and residents lack the appropriate role models — physicians who have integrated the psychosocial component into their practice and are able to teach the requisite approaches and skills.

The consistent challenging of the roles of health-care professionals and their relationships with patients and families will help clinicians to work with patients and surrogates in an open, compassionate fashion and do much to diminish conflict and champion the values and beliefs of the patient. The role of each professional on the caregiving team will need to be examined by the team as a whole so that expertise can be recognized and duplication avoided. Much will need to change for many of the professionals involved, for a patient/surrogate-focused process is not yet the norm.

Patient-centred treatment goals and decisions depend on a process of patient-centred deliberation. The relationship of trust necessary for deliberation is grounded in a shared decision-making process. Examining and capitalizing on the expertise of various team members,

and the continual development of their deliberation skills, will be key to involving surrogates in the process of patient-centred treatment decision-making.

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