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## **Decision making in a crowded room: the relational significance of social roles in decision making for allogeneic stem cell transplantation**

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### **Abstract**

Researchers studying health care decision making generally focuses on the interaction that unfolds between patients and health professionals. Using the example of allogeneic bone marrow transplant, in this article we identify decision making to be a relational process concurrently underpinned by patients' engagement with health professionals, their families, and broader social networks. We argue that the person undergoing a transplant simultaneously reconciles numerous social roles throughout treatment decision-making, each of which encompasses a system of mutuality, reciprocity and obligation. As individuals enter through the doorway of the consultation room and become 'patients' they do not leave their roles as parents, spouses and citizens outside in the hallway. Rather, these roles and their relational counterpoints - family members, friends and colleagues - continue to sit alongside the patient role during interactions. As such, the places that doctors and patients discuss diagnosis and treatment become 'crowded rooms' of decision making.

## Introduction

Since the mid-Twentieth Century, doctors have been obliged in law and policy to inform their patients of material risks involved in proposed treatments, and to obtain patients' explicit consent for those treatments. Legally and ethically valid consent now requires the fulfilment of principles of voluntariness, competence, specificity, adequate disclosure and understanding (Faden & Beauchamp, 1986). There are at least two serious criticisms of the current concept of informed consent. First, it is argued that patients may require different levels of competence in order to make different decisions, with higher levels of capacity needed to make decisions about treatment where the decision is more complex or where the consequences of that decision are more severe (Kerridge, Lowe & Stewart, 2009). Second, while clinicians may seek to provide comprehensive information about a treatment and present this in a way that minimises the possibility of coercion, they can do little to minimise the influence of patients' illnesses and social interactions on decision-making (Etchells, Sharpe, Dykeman, Meslin & Singer, 1996).

Recognition and promotion of patients' autonomy has recently become a central tenet of health care. In terms of health care practice, this has involved recognising patients' desire to be told of treatment alternatives and be involved in decision-making (Guadagnoli & Ward, 1998). At a theoretical level it has led to the development of models of decision-making in which patients actively contribute to a shared, negotiated enterprise. There are several models of shared decision-making including the informed decision-making model, the informative model, the interpretive model, the deliberative model and the professional-as-agent model (Brock, 1991; Charles, Gafni & Whelan, 1997; Emanuel and Emanuel, 1992; Gafni, Charles & Whelan, 1998). The models vary in the extent to which patients share their values and preferences, and also in terms of the point at which these values and preferences are incorporated into decision-making. The role accorded to physicians also varies from that of a medical expert whose role is to assess different treatment options and recommend to the patient treatment(s) with the greatest chance of success, to someone who is limited to performing technical, instrumental acts such as transmitting information. Identifying the need for a middle ground, Quill and Brody (1996, p.768) assert that patient choices "gain meaning, richness and accuracy if they are the result of a process of mutual influence and understanding between physician and patient". Advocacy for shared decision-making has been supported by research findings: involving patients in decisions about their own health, for example, has been shown to improve the quality of care and outcomes including better treatment choices and satisfaction (Powers, Goldstein, Plank, Thomas, Conkright, 2000), and can produce useful insights for both professionals and patients to use in disease management problem solving (Zoffmann, Harder, & Kirkevold, 2008). It has also been supported by patient education programs, by policy such as "patient empowerment" strategies (Department of Health United Kingdom, 2001, 2005) by communication aids such as question prompt sheets (Brown, Butow, Boyer, & Tattersall, 1999; Kinnorsley et al., 2008), and by lists of competencies for shared decision making for both patients and physicians (Towle & Godolphin, 1999).

Shared decision making has also been subject to criticism particularly relating to its implementation in practice. Most criticism centers on the fact that for patients to

engage fully in treatment decisions, they must develop an understanding of their condition and its treatment, and this task is easily accomplished only by individuals with good health literacy and access to information resources (Gambrill, 1999; Greenhalgh, 1999). The desire to be an active participant in decision making also varies between individuals and according to the circumstances of their illness. Many patients prefer to rely on physicians' advice when making decisions, especially for complex treatments (Mazur, Hickam, Mazur, & Mazur, 2005; Rodriguez-Osorio & Dominguez-Cherit, 2008), leading some to advise that physicians should take care when making treatment recommendations to patients (Gurmankin, Baron, Hershey, & Ubel, 2002; Karnieli-Miller & Eisikovits, 2009). Shared decision making is likely to be possible only when both patients and professionals adopt communication strategies that sanction and promote such interactions (Charles et al., 1997; Towle & Godolphin, 1999; Zoffmann et al., 2008). Additional limits are placed on the possibility of shared decision making by contextual factors, including visits to numerous practitioners for relatively short periods of time, or one-off consultations that reduce the scope for developing trusting relationships. Practical (including financial and organizational) constraints on the conduct of medical consultations and dissonance between doctors' and patients' preferences also restrict shared decision making (Gravel, Légaré, & Graham, 2006; Gwyn & Elwyn, 1999).

Some advocates of shared decision making have focused on the role of patients' values and treatment preferences (Charles et al., 1997). Although this is admirable in principle, there has been a tendency to view values and preferences as fixed, stable, and held latently in patients' minds, with it being the physician's task during consultations to draw them out (Brock, 1991; Emanuel & Emanuel, 1992). An alternative approach, which we advocate here, is that patients' values and preferences are dynamic and evolve over the course of an illness as a result of changes in knowledge and understanding, and shifts in the severity and trajectory of their illness and emotional states. Furthermore, patients' preferences for treatments are embodied, and evolve through the various roles they assume in social interactions and the way they position themselves in relation to health professionals, family members, and community members.

Shared decision making is commonly conceptualized as bounded by interactions between patients and doctors within the clinic. In contrast, we contend that decision making occurs over a longer time period than the consultation, and that it implicates the wider context of patients' daily experiences and relationships. Any investigation of patients' decisions to undergo medical treatment must therefore be viewed in relation to the other human actors and social institutions that impact on daily life. Although illness might sometimes be the dominant factor in a patient's experience, the obvious interrelationship between an individual's health state and his or her ability to engage in labor markets and social networks means that such factors are necessarily implicated in patients' decision making.

Similar to Lown, Hanson, and Clark (2009), we conceptualize decision making as a relational, interactive process. This contrasts with the more pervasive view of decision making as an individual cognitive process that occurs in steps based on the preconceived, fixed preferences of physicians and patients (e.g., Elwyn, Edwards, Kinnersley, & Grol, 2000). To fully appreciate the relational and embodied nature of

decision making, we draw from results of a qualitative study of people undergoing allogeneic bone marrow transplant.

## **Background**

Bone marrow transplant<sup>1</sup> (BMT) is also referred to as hematopoietic stem cell transplantation (HSCT), or hematopoietic progenitor cell transplantation (HPCT). Adults and children with malignant<sup>2</sup> and nonmalignant<sup>3</sup> disorders can, in some instances, be treated by bone marrow transplant. Depending on the disease and a range of other medical factors, the transplant might utilize stem cells derived from the patient (autologous transplant), or from a donor (allogeneic transplant; Copelan, 2006). In BMT, it is the hematopoietic precursor, progenitor, or stem cells—those which are destined to become all the cells that make up blood—that are transplanted. In Australia, the procedure is carried out by specialist hematologists attached to bone marrow transplant units in accredited hospitals.

Allogeneic BMT has an enormous physical, psychosocial, and emotional impact on patients and their families (Andrykowski, 1994). Patients require prolonged hospital admission and isolation during the transplant period. They often undergo numerous invasive medical procedures and experience a range of acute and chronic side effects and complications, many of which are life threatening and/or substantially impact on the recipient's quality of life. In addition, the patient experiences uncertainty regarding survival and the outcomes of therapy, profound changes in body image, and an almost complete loss of independence during the transplant phase. Paradoxically, the ideal time for patients to undergo transplant is the time at which they feel most well and their disease is not active; it is the forthcoming therapy that will cause them to feel so ill. Recognizing the importance of patient autonomy and the social nature of treatment decision making, it is widely agreed that any decision to proceed with allogeneic transplant should take into account both medical indications and the patient's wishes. That is, patients need to decide whether the potential long-term survival benefits outweigh the immediate transplant-related complications and morbidity (Silver et al., 1999, p. 1532).

The task of informing patients during the consent process is difficult for clinicians because of the protracted nature of the transplantation and the range and severity of the complications that recipients might experience as part of the transplant process (Carney, 1987; Little et al., 2008). There is a need for clinicians to provide ongoing information and support throughout the transplant procedure (Little et al., 2008). This provision requires differing roles for physicians (giving information, validating patient understanding, and team leading) and nurses (patient advocacy, patient education, and patient support) in the consent process (Carney). Because bone marrow transplant is such a complex process, it has been argued that the physician best serves the patient by offering his or her recommendation rather than remaining neutral (Patenaude, Rappeport & Smith, 1986).

## **Method**

In this project<sup>4</sup> we aimed to investigate the process of decision making in high-risk medical procedures, in this case allogeneic BMT, through in-depth interviews with patients, their significant others, and health professionals (including transplant hematologists), specifically concerning the process of consent to such a procedure. Health professionals and patients were purposively sampled from bone marrow transplant units of tertiary teaching hospitals in Sydney, Australia. For each patient in this study, the transplant (potentially) offered either cure or increased long-term disease-free survival.

In consultation with a transplant hematologist, we decided at the study design stage to restrict the study to patients who agreed to undergo allogeneic BMT. This was the case because, in practice, few (if any) patients offered a BMT refuse to undergo the procedure, primarily because it offers them their best—if not only—chance of long-term survival. BMT is often an anticipated part of many patients’ management plan from diagnosis. Patients are usually referred to a specialist BMT unit for consideration of transplantation only if it has been decided that transplant is an option for them, if they are “fit enough” to survive the rigours of the transplant, and if they have already indicated a willingness to undergo the procedure. All participants (including patients) were offered a choice whether or not to participate in this study. It was explicitly stated to patients and their significant others that their decision about whether or not to participate would not influence the care the patient received.

Patient participants were purposively sampled on the basis of their agreement to proceed with transplant and their fluency of spoken English. In referring patients to us for invitation to be included in our study, the transplant hematologist recommended only patients whom they believed to be without significant psychological distress and who were not already overburdened by enrolment in other (clinically based) research. Our sample of 16 patients ranged in age from 35 to 66 years, with 10 participants aged in their 50s at the time of transplant. Ten of the participants were men and 6 were women. All were city or urban dwellers, and came from a range of socioeconomic circumstances and educational backgrounds. Their specific hematological malignancies varied; however, all were being treated with allogeneic (rather than autologous) bone marrow transplant. Ten were Australian-born, four were European, and two were from the Americas. Of the 16 patients who participated in the study, 7 were interviewed once, 8 were interviewed twice, and 1 was interviewed three times, resulting in a total of 26 interviews. Repeat interviews were conducted to provide patient perspectives both before and after the procedure. Patients were asked to nominate a “significant other” who was involved in the decision to undergo a transplant. This led to 10 interviews with referring (nontransplant) hematologists, a social worker, spouses, and children. Seven transplant hematologists and nine allied health professionals were each interviewed once, except for a transplant coordinator who was interviewed twice. In total, the data set comprised 53 interviews (see Table 1).

**Table 1.** Interview Data Set: Numbers of Participants and interviews

	Participants (number)	Interviews (number)
Transplant physicians	7	7

<b>Allied Health (including Nursing)</b>	9	10
<b>Patients</b>	16	26
<b>Significant Others (patient-nominated)</b>	10	10
<b>Total</b>	42	53

Patients were asked about how they had made the decision to undergo transplant in relation to their interactions with professionals and their personal circumstances. Professionals were asked to talk in a general way about how patients approached the transplant and not about particular individuals, because of our interest in the professionals' general approach to informing patients about the transplant and gaining their consent for the procedure. Occasionally, however, the professionals did refer to specific patients, including those who had been interviewed for this study. Such data gave us greater insight into these cases; however, we did not use these data to confirm the accuracy of participants' recounting of interactions. We were not interested in the "correctness" or "incorrectness" of people's recollections of interactions between patients, their families, and the hospital care professionals. Rather, we were concerned with how patient participants talked about their interactions with health professionals and members of their social network in relation to the decision to proceed with BMT, and how the activities and opinions of these others were implicated in their decision making.

All 53 interviews were analyzed with a focus on information giving, interpersonal relationships, and the emotions that participants brought to bear on the consent process and experience of the transplant. A broad coding framework was developed and constant comparison used to strengthen, collapse, and expand different concepts. The data presented in this article are from a particular subset of the coding framework in which we sought to identify medical and social factors present in patients' decision making. We interpret and discuss these factors as evidence of particular social roles.

## **Results**

### *Medical factors:*

*Disease characteristics and the need for transplant.* Patients and their significant others identified that the type, stage, and progress of their disease, and particularly the experience or possibility of relapse, led to them viewing allogeneic transplant as their only realistic treatment option. Concurrent to this was the perception that the current state of the patient's condition offered him or her a "bleak choice" (Hawkins & Emanuel, 2005, p. 18) between certain death without the transplant and the uncertain possibility of survival from receiving the transplant. The time-critical nature of their decision making and the need for a transplant to happen soon were also emphasized:

It's obviously not something that they're forced into, but I think sometimes they're pretty much told that, "Well, you've got no other option really. If you want to live then you need to have a transplant." (Social worker)

When I was told a bone marrow transplant was an option, that it was a bit of a light at the end of the tunnel, because . . . with this aggressive form of cancer I'm not going to live more than six or eight weeks so . . . it really was never an option. . . . Because it is my only hope—it's the difference between life and death, and it happens to be that it needed to be done quickly in order to avoid what would otherwise be inevitable. (Patient)

*Expert opinion.* Many of the patients and their significant others described the decision to proceed with the BMT as a reflection of the advice they had received from their referring hematologist and transplant hematologist:

[Transplant hematologist] said from the word go, "You're going to Sydney, you're going to have a bone marrow transplant. . . . He said, "I think we should have a bone marrow transplant." (Patient)

As far as approaching the whole thing, you know, and should I or shouldn't I, um obviously you've got to rely on, you know, medical advice, because in my situation it was a case where it was really no other option. (Patient)

Well [transplant hematologist], he was the specialist over there, he got us in and everything else, and had a talk to us, and said, "You know there's no option. You'll be having a bone marrow transplant probably before Christmas. (Significant other)

Patients thus positioned themselves and were positioned by others as passive in decision making. They did not resist this, but perceived that the physicians accurately identified what their best interests and associated preferences were, and acted consonant with these. Here, medical professionals were the dominant, legitimized providers of transplant treatment. These physicians were viewed as highly specialized, possibly because of their subspecialization as "transplant hematologists," as distinct from "hematologists" (referrals to transplant hematologists are made by general hematologists rather than by general, nonspecialist practitioners).

*Procedural aspects: relative benefits and positive outcomes.* Procedural aspects concerning the relative benefit of the transplant to the patient were also important factors in his or her decision making. The very fact of finding a suitable donor and being offered the BMT influenced patients' decision to undergo the procedure. One patient commented,

I'm just very, very lucky I've got a donor. Like if I didn't have a donor I wouldn't be sitting here with this option of, you know, being cured . . . so I think for me it was a pretty clear-cut decision.

A transplant coordinator expressed concern that patients' excitement needed to be tempered by an appreciation of the risks of the procedure:

Their first focus is, "Do I have a donor?" and if that is identified then that's a big cause for celebration . . . so um, they're very usually quite upbeat about it at this stage. I would think that they're not that aware of what the risks are and what the complications might be, and their chances of cure, really.

Although the patients recognized the prospect of a bad outcome, they also said that to be offered the transplant at all meant that they had a good chance of having a positive outcome:

He [transplant hematologist] was very straightforward, just saying, "This is the case, that you know you either have a bone marrow transplant, um which should have a successful outcome and we get rid of the leukemia. Or if you decide not to do that, that's fine, but you know you've probably only got a 10% chance of being around in the next two years." (Patient)

### *Social factors*

*The will to survive.* Patients' desire to live so that they could participate in important social events and mark particular milestones was a particularly salient feature of their decision to undergo transplant. As part of this general desire to live, patients commented on their desire to attend particular family milestone events rather than attend to any financial or employment responsibilities, or individual achievements:

The patient is making the decision based on a lot of things that I'm probably not aware of—daughter's marriage, um, will I live to see the summer, rather than will I live another three or ten years. (Transplant hematologist)

I know one of the things that went through my mind was . . . that I wanted to be around to be a grandmother. I kept thinking . . . I'm too young, and I want to see my children married with children. And um knowing that the transplant was the one way that I would have a new lease on life, and that would be the way for me . . . to be around long enough to see my grandchildren. (Patient)

Although specific events were important to patients, it was a more general desire to go on living, and the "bleakness" of the choice that they faced, that most influenced their decision making. This will to survive might be considered a foundational value of the human condition (Little, 2004):



I don't know if it's the disease, but it's basically their wish to live that's doing that. You know . . . if you didn't really care, then you might not even consider such a risky procedure, but it's basically they want to live, they're either young, they've got a family to live for, they've got things they want to enjoy so they want to extend their longevity . . . that's the aim of the transplant. . . . So you can have a more normal er, life, er normal duration, normal lifestyle, normal time, so it's not the disease itself that's coercing them it's their wish to return to normal and be, live the normal lifespan that's expected for their age. (Transplant hematologist)

*Family relationships: practical needs and attitudes towards transplant.* Patients often perceived their family's reliance on them as a reason to go ahead with the transplant. One patient talked about her family's emotional needs: "I'm going to do it for myself and I also want to do it for my husband, because I really think without me he'd be lost. He acts real tough, but he's not." Another patient identified her family's practical needs: "I don't want to leave my husband or my son. I love both of them very much, and their housekeeping skills are dreadful." Two patients specifically mentioned the responsibilities they had for looking after family members with their own health issues:

It's primarily for them because I'm selfish, I'm not ready to go yet . . . My older daughter has had [a chronic illness] in the last four or five years, so she needs a mother to look after her.

I thought well, I've got to do this because he [husband] needs a carer and I didn't want him to feel as though he had to be a burden to either one of the kids. . . . I had to do the thinking, I had to do everything. Make sure his prescriptions were filled, otherwise he wouldn't think to do that. He'd sit in the chair and watch TV [television] all day.

The attitude of patients' families toward the transplant was also a crucial factor in the decision-making process. In some cases, patients' families were initially unsupportive of them undergoing the transplant; however, this attitude subsequently changed to be supportive once the risks of refusing the transplant were made explicit:

My mum's very religious. And she, um, at first she was very scared. She didn't want me to do it. But then when she spoke to [transplant hematologist], he sort of opened up her eyes a bit more. And since that she changed. (Patient)

In other cases, the professionals observed that there were times when the patient did not want to have the transplant but their family did, and the patient ended up going ahead:

My feeling personally is that it's, it should be the patient's decision; however, I'm sure many do succumb to family pressure . . . doing it for the kids or doing it for their partner. (Transplant coordinator)

I can think . . . of comments being made from the doctors that . . . “The wife really wants him to have it.” . . . They’re thinking about pulling out or that kind of thing . . . I suppose often the case that . . . the spouse or whoever might um, want to keep going and the patient may not or . . . they might keep going because they don’t want to say no to the wife. (Nurse)

The strength of the patients’ commitment to their family as their reason for going ahead with the transplant was noted by one of the patients:

I was probably very, very afraid of how it’s going to, what’s going to happen after the transplant. That’s probably why I didn’t want to do it but, end of the day, to be quite honest with you, I have done it for people around me. If I was on my own, no family, no wife-to-be, no mother . . . no father, honestly, I wouldn’t, I wouldn’t do it. But out of all instances, like, even my girlfriend . . . she’s been so good, the very first time I’ve been sick, and even when I was here, I said to myself, “If I’m not going to do it for myself, I’ll do it for her,” she deserves to be better than that.

Family support for the transplant was usually subtle, as indicated by another patient:

My two adult daughters and my husband are probably the most closely related in terms of dialogue . . . they couldn’t come to the [appointment] here with [transplant hematologist], but whenever I’ve consulted my hematologist in [the hospital] they’ve been there asking very good and relevant questions. . . . It’s never occurred to them that I might not have it [the transplant], either. I don’t think I’d be allowed not to have it.

In addition to this subtle support, some family members, particularly spouses, gave much more explicit encouragement to patients to go ahead with the transplant:

Well Jamie said from start to me, “Dad,” he said, “you have to do transplant you know . . . you have to.” . . . He was very keen. Even my wife, you know . . . yeah, they was very keen. (Patient)

At that stage I was 50/50. I didn’t want to, and my husband’s saying, “You’ve got to have it” (Patient)

And even if I had doubts I would have made the decision because of him [husband], because he was so, “This is what you have to do.” (Patient)

This explicit encouragement was also recognized by the patients’ spouses:

I guess I sort of leaned on her and I said, “Look, we’ve really no choice, we’ve got to go through the bone marrow transplant.” . . . Logically, she knew that was the way to go, but she needed somebody to give her a push and I . . . got

my daughter to do that, the same thing, [but] my son I think was too frightened to get involved. (Significant other)

I told her, you know, well she knew my opinion right from the start. . . . “Well, you’re having it.” Um, she was a bit skeptical, and she was, “Well, you know, it’s my final say,” and I said, “Yeah, I know it’s your final say.” But to me it was just, “Well, sorry darling, you’re having it.” (Significant other)

*Support network.* Support from social contacts outside their immediate family was also implicated in patients’ decision making:

I thought, “Should I do this or should I not?” . . . But then I thought to myself, “Stop being silly. Snap out of it and do it,” because I don’t, if people give you support I can’t let them down. . . . There are people, a lot of people put their faith in you, and you think to yourself, “You just can’t be a coward and not do it.” . . . People help you . . . and for me to pull out...when everyone’s trying to help you out, it’s not the right thing to do. (Patient)

For another patient, her employment at a local school led to her having a large support network:

Something of the confidence that I’m not completely alone and, um, if I never believed in the power of prayer I’d have to be something stupid not to believe in it now, when you’ve got kids all over [the region] praying. . . . There’s a real sense—a real spiritual sense there that I couldn’t possibly have done this on my own.

In another patient’s case, it was a local church group who provided her with support:

On Easter Monday they actually had organized an all-night prayer vigil for me, which was unbelievable. . . . I couldn’t imagine that people were that committed, that [they] would want to actually go on a roster to be up all night to say prayers, was just unbelievably uplifting. And that is a fantastic experience I’ve had, to then be able to take and use as a source of strength.

Practical support was also identified as important by one of the significant others:

We’ve got a [small] business . . . so the daughter was running that, so we just got casual staff in and they worked extra hours, ‘cos they knew what was going on and what had to be done. . . . We were extremely lucky there.

The factors presented above were implicated in patients’ decision making to different extents. Although the desire to avoid death, the urgency of the disease state, the transplant hematologist’s expertise, and the imperative created by the availability of a donor were dominant, all patients also talked about the importance of not letting people down. We now turn to a discussion of the way the factors

identified above, in combination with their interactions with other people, led patients to adopt particular roles in relation to their illness.

## **Discussion**

Our analysis highlights the complex range of factors that influence patients toward transplantation. Each of these medical and social factors is implicated in the numerous roles that patients fulfill as they make treatment decisions. These roles are concurrent; they overlap and all are reciprocal. Patients themselves have a sense of what it means for them personally to fulfill these roles, whereas other people (health professionals, family members, colleagues) have expectations about how the sick individual will fulfill these roles.

We do not define one way of being a patient, spouse, parent, or community member, but rather take an interactionist perspective (Biddle, 1986; Strauss, Fagerhaugh, Suczek, & Wiener, 1985; Stryker, 2002; Turner, 2002) to look at how roles are negotiated. That is, we are concerned with the way the patterning of individuals' behavior that constitutes roles arises initially and recurrently out of the dynamics of interactions and in relation to other actors (Turner, 2002)—in our case, the relation of patients to health professionals, family members, and people in their broader social network. We are also not concerned with role conflicts or role strain (Hardy & Hardy, 1988), but instead with the roles people embody in their decision making about high-risk medical procedures such as allogeneic BMT.

The next three proposed roles—patient, spouse/parent, and citizen/community member—encompass both local, interactional, and societal levels. At the societal level, these roles develop longitudinally and are made apparent to the individual through the media and interactions with unfamiliar people outside of their medical, familial, and social settings. Crucially, the boundaries of what constitutes acceptable behavior from individuals in these roles are not fixed, and remain constantly evolving and shifting. These roles at the societal level are normative in the sense that they construct what the individual ought and ought not do, and create reciprocities and obligations. Locally, these roles are those in which the patient interacts with other individuals. Within these interactions, these roles carry with them expectations from their counterparts, and establish additional commitments of mutuality, obligation, and reciprocity.

### *Patient: Relations With Health Professionals*

In the initial stages of becoming a patient, three processes generally occur to the individual person. Typically, the individual experiences bodily processes that disrupt his or her usual state of health or wellness. Second, the individual enlists the help of other individuals who are expert in the internal (perhaps invisible) bodily processes they are experiencing. Third, the individual engages with nonhuman agents such as devices and medications that are recommended by the expert human agent, and to which they provide access. The second and third of these processes are undertaken by the individual because of their perceived abilities to identify, treat, and alleviate or cure the discomfort of the first (disagreeable) process. For the participants in our

study, their hematological condition originated in their experience of somatic symptoms that differed from their usual experience of wellness. By the time they were considered for a transplant, they had often been diagnosed with their condition for a number of years, had undergone previous treatments, and experienced disease relapse (in some cases more than once). In this scenario, medicine defined the transplant as their best, if not only option for cure or increased survival.

By taking up the role of the sick person and seeking the advice of individuals who are expert in identifying and treating their experience as symptoms of a condition, the sick person comes to be constituted as a “patient.” Parsons’s (1951) notion of the sick role identified illness as a social role involving certain exemptions, rights, and obligations shaped by the society, groups, and cultural tradition to which the ill person belongs. Individuals experiencing illness are obliged to seek and cooperate with help from a recognized medical practitioner. Medical practitioners’ expertise enables them to recommend diagnostic procedures and treatment (including devices and medications) that they believe will improve the patient’s condition. Although Parsons’s functionalist foundation does not account for patients’ approaches to dealing with chronic illness (Freidson, 1970; Segall, 1976), nor for current organizational and professional contexts for doctor-patient interaction (May, 2007), nor the involvement of actors in patients’ broader social networks in patients’ experiences of and activities surrounding illness, the part of Parsons’s formulation that is crucial to our analysis is its focus on the necessity of patients taking action with the intention of returning to a healthy state or managing their illness. This occurs primarily through their engagement with expert practitioners. The definition of the person as sick and their employment of other people in alleviating or managing their illness identify the patient role as unavoidably and intrinsically relational.

Relationships and interactions between physicians and patients have traditionally been understood in terms of a significant power differential. Patients’ lay positioning arises from their ability to report symptoms and relate illness narratives; however, they lack medical knowledge and the expertise to objectify their subjective experience and identify solutions. As such, they must rely on another expert person for this. Health professionals legitimize patients’ illness experience as a disease entity which is constituted by a set of “symptoms” with prescribed treatments. Medical practitioners as experts have special power to assign diagnoses and recommend treatments based on their knowledge of medical nomenclature, research evidence, and experience of treating other patients. Their expertise is reinforced by their legal entitlement to prescribe medications and to undertake interventions not available by other means. In this study, the highly specialized nature of the transplant and the professionals performing it was reinforced by the referral of patients to the transplant centers by nontransplant hematologists and the availability of the transplant procedure at only a selective subset of hospitals in Australia’s largest cities.

As a logical progression from diagnosing a patient’s illness and identifying possible treatments, a physician also often recommends their preferred treatment(s). This recommendation will most usually be based on consideration of the best possible

outcomes for the patient; however, it is also likely to include consideration of the particular services available at their health care facility and the physician's knowledge of their individual and clinical team expertise. The skill of the physician in recommending treatments constitutes additional evidence of his or her professional expertise.

Physicians, as members of the medical profession, have traditionally carried with them not only a claim to mastery of medical knowledge but also social power that manifests in consultations with patients. This social power has been central to analyses of decision making, where it has been thought that patients consent to treatments not because they understand the medical reasoning behind them, but rather based on their trust in the physician as a person and as a representative of the profession (Parsons, 1951). It might also be the case that for patients, this act of acquiescence to the physician's recommendation serves an important function of demonstrating their trust in the physician's expertise, as well as contributing to developing and sustaining the physician-patient relationship. This demonstrates the significance of relational aspects more than instrumental facts in decision making, although, of course, it is impossible for patients to access many medical treatments without the sanction and recommendation of their doctors.

In our introduction we described the trend toward shared decision making in clinical practice. This strategy aims to decrease the control exerted by professionals in health encounters and empower patients by increasing their involvement in treatment decisions. It demands a shift in the expectations and communication styles of both patients and physicians (Charles et al., 1997; Towle & Godolphin, 1999) toward more collaborative, negotiated interactions. A prominent aspect of this has been the increased provision of medical information by practitioners (Kinnersley et al., 2008) and on the Internet (Hardey, 1999).

Shared decision making has proved difficult to achieve in practice, however. Patients vary in the extent to which they prefer to adopt active roles in decision making (Rodriguez-Osorio & Dominguez-Cherit, 2008). In addition, the competence gap (Tuckett, Boulton, Olson, & Williams, 1985) remains difficult to breach, and many patients prefer to follow their physician's recommendation (Mazur et al., 2005). In this study, patients and their significant others often recalled physicians' opinions being expressed in directive, matter-of-fact terms. Patients deferred to physicians' recommendations, and many asked their physician directly what they would do in a similar situation. This is consistent with previous research that suggests patients give considerable weight to physicians' recommendations in their decision making (Gurmankin et al., 2002). Adopting the expert clinician's opinions can be viewed as an active choice by patients rather than a relinquishment of the right to decide. In this study, physicians' interpretations and recommendations predominated in decision making over patients' perceptions of the risks posed by the transplant, serving to demonstrate the greater significance of personal and affective factors compared to information in patients' decision making. It also reveals decision making to be a relational process rather than an individual cognitive activity.

*Spouse/Parent: Relations With Family Members.*

Societal perspectives on familial roles point to normative ideals of contribution and reciprocity of parental and spousal members. Idealized parenting behaviors differ between gender groups and cultures (Julian, McKenry, & McKelvey, 1994). In Australia a good parent is seen to be one who spends time in face-to-face contact with children and who acts as a good role model. A good spouse is one who contributes equally to the relationship, attends to the business of the family, and provides emotional, practical, and financial support. These expectations are challenged by acute or chronic illness, which place strain on individuals fulfilling such roles (Mui, 1992).

Reciprocities and obligations of patients to their family members was a particular feature of participants' accounts in this study. Participants described practical, financial, and emotional support functions they fulfilled within their families. These reciprocities, in which patients frequently constructed their family as dependent on them, served to highlight the limitations the patients' illnesses had placed on their ability to fulfill their social roles. Financial constraints were particularly prominent in patients' accounts. All of them had needed to limit their paid employment because of their prolonged inpatient treatment, fatigue, and other symptoms of their illness, as well as their requirement to attend numerous hospital appointments. This was particularly problematic for older patients who, if they survived the transplant, would have restricted capacity to earn more income before they retired. Patients' ability to fulfill a parenting role was also affected, often permanently (Barlow, Cullen, Foster, Harrison, & Wade, 1999; Elmberger, Bolund, & Lützén, 2005).

Other family members' roles are also affected by the long-term illness and incapacity of one family member (Aldridge & Becker, 1999; Covinsky et al., 1994). In this study, as family members adopted caring roles and allowed patients to be suspended from their usual role duties, family members' abilities to fulfill their usual roles were also restricted. Family members' ability to work outside the home was often reduced, in turn limiting the income of the entire family. Patients often require increased social support from their families. Such support has been shown to improve both the quality of life (Molassiotis, Van Den Akker, & Boughton, 1997) and mental health (Kettmann & Altmaier, 2008) of transplant patients.

The possibility of survival suggested by the transplant offered patients the potential to return to their pre-illness family roles. Baker and colleagues have shown that many transplant patients have difficulties reintegrating into their former social roles post BMT, and that role retention is related to higher quality of life for transplant patients (Baker, Zabora, Polland, & Wingard, 1999). A successful transplant also offered the potential for other family members to be restored to their normal social roles. This possibility was recognized by both patients and their significant others, and it clearly influenced patients' decision making. Family members gave both implicit encouragement and explicit commands to the patients to undergo the transplant. This support was central to patients' decision making, with many patients viewing undergoing the transplant as necessary for reciprocating the support given to them by their family during the course of their illness.

The relational nature of patients' decision making was reinforced by the centrality of family issues in discussions about how they came to have the transplant. Family members were involved throughout the process; they attended hospital

appointments and participated in discussions of the risks and benefits of the procedure. Most often, patients' attitudes toward the transplant were consonant with those of their families. Family members' opinions were expressed both implicitly and explicitly, with transplant seen as a possible means through which all members (including the patient) could resume previous family and work activities. Patients positioned themselves as central to their family's functioning, and this in turn justified the need for the transplant.

#### *Citizen/Community Member: Relations With Social Networks*

Through the role of a citizen, the individual contributes to society as a whole politically (e.g., through voting), economically (e.g., through work and taxation), and biologically and socially (e.g., through child bearing and rearing). Reciprocities and obligations, similar to those of the patient and family member roles, are also apparent in the citizen/ community member roles. Sick people might have the expectation of active contribution suspended because of their incapacity, although there is an expectation that the individual will try to recover from the illness and thus resume his or her civic role.

In this study, social networks offered patients emotional and practical support with an implicit expectation that the patient would do everything he or she could to become well and reengage as a full participant in the community. This created an implied obligation for patients to go through with the transplant, as commented on by one patient, who said, "For me to pull out . . . when everyone's trying to help you out, it's not the right thing to do." Similarly, patients were often part of a working community that had made concessions regarding their working hours and job responsibilities because of their illness. These support networks mobilized subtle expectations, consistent with the expectations of patients' families, in influencing patients toward having the transplant as a means of (potentially) recovering from their illness and resuming their usual community roles. The implications of these expectations in patients' decision making serve to emphasize the relational nature of the decision-making process.

For patients who survived the transplant, ongoing illness or incapacity because of treatment, emotional impacts of illness, and attendance at follow-up appointments provided physical, psychological, and logistical challenges that placed limitations on the possibility of transplant survivors completing their social roles in the ways they did before they were sick. This led to patients finding new ways of defining what "normally" engaging in their social roles meant within a framework of "cancer patientness," which has been shown to endure even years after the patient has survived their illness (Frank, 1995; Little, Jordens, Paul, Montgomery, & Philipson, 1998; Montgomery, Jordens, & Little, 2008).

#### **Conclusion**

The results reported here reveal the extent to which decision making is a relational process rather than a predominantly cognitive activity where patients rationally weigh facts and evidence and combine them with their physician's recommendations



to choose the treatment with the highest chance of the best medical outcome. Current shared-decision-making models have gone some way to recognizing the importance of social and interactional aspects by identifying communication strategies for professionals to enhance patient involvement in decision making (Charles et al., 1997; Towle & Godolphin, 1999; Zoffmann et al., 2008). We argue, however, that these models require extension to include consideration of the influence of family and community environments, and the construction of a variety of social roles, on patients' decision-making processes. As demonstrated above, the interrelated impacts of the physician's expert opinion and the importance of actively contributing to their family and community shows patient decision making to be an inherently social, relational activity.

It is clear from the patient, carer, and health care professional narratives reported here that social roles (including those related to illness) are complex and interrelated. Decision making is not a process undertaken solely by physicians and patients. As sick individuals enter through the doorway of the consultation room and become patients, they do not leave their social roles outside in the hallway. Rather, the person sitting opposite the clinician might be simultaneously embodying roles as an individual with somatic experiences, a patient laboring under the expectations of acting correctly as a sick person, a spouse and parent with both interpersonal and societal responsibility, a member of a social network, and a citizen. These roles and their relational counterpoints of other family members, friends, and colleagues continue to sit beside the patient role, and are all implicated in the decision-making interaction that unfolds between the patient and the physician, so constituting the "crowded room" of decision making.

In this study, the scope for negotiating about whether or not to proceed with the transplant was limited as a result of the "bleak choice" facing the patients: certain death without transplant compared to the possibility of survival from receiving the transplant. But although this bleak choice (Hawkins & Emanuel, 2005, p. 18) might make the decision itself relatively straightforward, the variety of social roles implicated in decision making are complex and evolving. We suggest a shift in thinking around decision making, from examining how patients understand medical information and decide on treatments based on their best option clinically, to viewing decisions as embedded in social relations of obligation and reciprocity.

Shared-decision-making models locate decisions within interactions between health care professionals and patients in clinical settings. If we accept this to be the case, then the roles that the participating individuals assume appear to be straightforwardly those of physician and patient. In this article, however, we have argued that the process of decision making occurs over a long time period and in spaces away from the clinic. In these other times and spaces, the patient embodies social roles that can include spouse, parent, and community member. The decision to undergo BMT is made on the basis that it offers the possibility to resume these roles. The centrality of these roles to patients' decision making is demonstrated by the fact that patients in this study used their role obligations as justification for undergoing a transplant.

The study findings emphasize the importance of considering relational and affective aspects to patients' decision making, rather than considering only instrumental

actions such as information giving or competencies such as health literacy as the basis for decision making. Our analysis of the roles patients fulfill as they make treatment decisions demonstrates the interrelated nature of the patient role and family and community roles in decisions to undergo treatment. Although the medical reasoning behind offering patients a transplant might appear obvious, the normative boundaries and role obligations surrounding these other social roles are potentially unstable, and shift over time with changes in social circumstances and disease states.

Social roles constitute the contexts in which patients give meaning to the medical facts of their case. Clinicians thus need to be aware that changes in the social circumstances and roles outside of the patient role might influence the process of decision making, even though the final decision itself might not change. This finding points toward the need for future research into how evolving social environments shape the familial and community roles people adopt, and how these roles intersect with the patient role and medical decision making.

Although research to date has focused on particular interactions occurring at individual sites, namely physician– patient interactions within consulting rooms and hospitals, we instead draw attention to the complex network of factors and roles that patients negotiate in spaces and times that extend beyond those at which health professionals are present. Decision making must therefore be viewed as a longitudinal process that occurs not just while patients think about the relative importance of different aspects of their circumstances, but also how they simultaneously exist, how they perform, and how they are patients, spouses, parents, and citizens.

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### **Notes**

1. Because bone marrow was the original source of stem cells back in the 1960s, bone marrow transplant is the term most often used, but it is the self-renewing population of cells— the stem cells taken from the bone marrow and other blood sources—that are actually transplanted and renew in the recipient.
2. Leukemia, lymphoma, myeloma, myelodysplastic syndrome, certain high-risk solid tumors.

3. Thalassaemia, osteogeneses, autoimmune disorders, bone marrow failure syndromes, metabolic storage disorders, and immunodeficiencies.
4. Approval to conduct the research was received from the relevant university and area health service human research ethics committees.

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