

Optimising consent and adherence in high-risk medical settings: nurses' role as information providers in allogeneic bone marrow transplant

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Abstract

Complex medical procedures such as allogeneic bone marrow transplant (allo-BMT) require extensive medical and psychosocial information to be communicated to patients. Whereas, previously, patients only received information from their doctor and only during consultations, increasingly they access information in various modalities, from numerous sources and from a range of different health professionals, and at different times throughout the course of their illness and treatment. We present qualitative data from interviews with patients and nurses reflecting on information provision during allo-BMT. Patients' vulnerability and the unpredictability of transplant outcomes highlights the necessity for, and importance of, ongoing information support. In this paper we highlight the role of nurses in supporting patients' and families' informational needs throughout the transplant trajectory. Nurses have a critical role in ensuring that patients receive relevant, rigorous and salient information during the course of allo-BMT so that their autonomy is respected and their adherence and capacity to cope is optimised.

Consent, complexity and the bone marrow transplant process

The complexity of bone marrow transplant (BMT) for both patients and practitioners is well established¹. Before treatment can take place, patients are required to provide consent to the intervention. A patient's consent is contingent on them having been provided with information that is 'material' to them, that is to say, is of relevance to their decision-making. Consent can only be considered to be valid after the patient has not only been provided with material information but has also understood it to the degree they desire in order to be able to make an 'informed' decision about whether or not to proceed with the intervention under consideration. Information provision forms part of the element of 'disclosure' that, along with 'competence'

and 'voluntariness', enables a valid consent to be obtained where it is felt that "[t]he opportunity for voluntary decision-making is only present where there has been adequate disclosure by the health professional"^{2(p333)}. The information provided by health professionals to patients must therefore include comprehensive information about the benefits and risks of the proposed treatment, and any alternatives²⁻⁴. This information includes effects of treatments on both patients' physical health and the social implications of decisions to proceed with such procedures.

It is important that, as part of the consent process, health professionals employ a range of information transfer skills – assessing patients' capacity, knowledge, information preferences, values and health literacy – so that they can provide information

in a form that the patient wishes and can comprehend. This is an important skill because patients' understanding of information varies according to their preferences, values and literacy competencies^{5,6}. Increasingly, patients now source information themselves about their conditions and treatments through the internet⁷⁻⁹. However, many patients often have difficulty relating this information to their own situation or assessing the trustworthiness of the information they find. Health professionals therefore play a key role in helping patients interpret information they find online¹⁰.

The complexity of information provision is further heightened in the case of high-risk procedures with uncertain outcomes such as BMT. While information disclosure about complex therapies is frequently imagined as occurring at a single time point – and often in a calm and controlled environment prior to the commencement of a procedure or treatment – this is overly simplistic as information about complex therapies and/or chronic conditions is, of necessity, generally provided at multiple times and in different contexts over the course of a patient's illness¹¹. This was certainly the case we present here which investigated how consent was negotiated with patients undergoing allogeneic bone marrow transplant (allo-BMT).

Allo-BMT is a highly complex procedure composed of many individual procedures that may include, but are not limited to, the insertion of central line, administration of sub lethal chemotherapeutic agents, irradiation, blood tests, biopsies, insertion of nasogastric tube, pain medication and infusion of donor cells. Each of these procedures carries a degree of risk and/or discomfort, and requires the provision and reiteration of information and confirmation of ongoing consent from the patient¹².

As such, BMT has an enormous physical, psychosocial and emotional impact on patients and their families¹³. Patients require prolonged hospital admission and periods of isolation during the transplantation. They often undergo numerous invasive medical procedures and experience a range of acute and chronic adverse effects, many of which are life-threatening and/or substantially impact on their quality of life¹⁴. In addition, the patient experiences uncertainty regarding their survival and the outcomes of therapy, profound changes in body image, and an almost complete loss of independence during the immediate post-transplant phase^{15,16}. The psychological impact of these effects is heightened because, for many patients, transplant represents their best and/or last hope of cure whilst simultaneously exposing them to their greatest risk of death.

The complexity and time-consuming nature of the BMT process therefore means that multiple health professionals need to be involved to adequately support patients across the whole timeline of the BMT¹⁷. The protracted nature of the transplantation and the range and severity of the complications

that recipients may experience as part of the transplant process make it necessary for nurses to provide ongoing information and support to the patient throughout the transplant procedure¹⁸. Nurses' expertise in patient advocacy, patient education and patient support are particularly central to the ongoing consent process in this setting¹⁹.

It is noteworthy that it is impossible and impractical – and also legally and ethically unnecessary – for health professionals to provide all information about BMT in an attempt to obtain 'fully' informed consent. Legally, medical practitioners have a duty to exercise reasonable care and skill, both in the provision of professional advice, as well as in their diagnoses and treatment of patients. In the decision in *Rogers v. Whitaker* [1992] HCA 58, the High Court held that a responsible medical practitioner is to provide the patient with relevant information about material risks. A risk is considered material if a reasonable person in similar circumstances would attach significance to the risk, or if the doctor is, or should be, cognisant that the particular patient would express concern about the risk. This principle is also consistent with the guidelines from the National Health & Medical Research Council (NHMRC)²⁰.

What is instead required is for health professionals to satisfy themselves that patients have "demonstrably engaged" with the education process and that the consent they provide is valid²¹. Additionally, much of the available evidence regarding the success and effects of the procedure has been analysed at a population level, and this creates one of the greatest challenges faced by clinicians in the BMT process – how to translate this information from a population level for an individual patient and their circumstances. Nurses' skills lie in overcoming this dissonance to effectively translate this evidence for individuals and adequately support patients emotionally as they learn to interpret and apply this information to their individual situations²².

Elsewhere we have presented a detailed analysis of how patients and their families in our study understood consent to BMT as a complex, relational decision-making process "embedded in social relations of obligation and reciprocity"^{23(p1269)}. Here we detail patients' and nurses' perceptions of the complexity of information delivery and support across the transplant trajectory. We draw attention to the centrality of nurses' roles and their expertise in supporting patients' information needs throughout the transplant process.

Method

This research formed part of a larger project aimed at investigating the process of decision-making in high risk medical procedures – in this case allo-BMT – through in-depth interviews with patients, their significant others and health professionals²⁴. Health professionals and patients were purposively sampled from BMT units of tertiary teaching hospitals in Sydney, Australia.

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Our study included four groups of participants – transplant haematologists, nurses and other health professionals in the transplant team, patient-nominated significant others, and patients. In total, the data set comprised 53 interviews. Nine nursing and allied health professionals were interviewed, including six nurses with varying roles such as transplant coordinator, clinical nurse consultant and ward nurse.

A total of 16 patients undergoing allo-BMT were included in the study; 8 were interviewed twice and one was interviewed three times, resulting in a total of 26 patient interviews. Repeat interviews were conducted in order to provide patient perspectives both before and after the transplant.

We decided at the study design stage to restrict participation to only those patients who had already consented to undergo allogeneic BMT since few, if any, patients who are offered a BMT subsequently refuse. It is usually only those patients for whom it is thought that BMT could be a therapeutic option, are considered 'fit' enough to survive the rigours of the transplant, and have already indicated a willingness to undergo the procedure, who are referred to a specialist BMT unit for consideration of transplantation. Only patients deemed to be fluent in English were included in the study because the research team did not have expertise in using translated interview data and had concerns about the accuracy and nuance of patients' responses being lost through translation. We acknowledge this as a limitation of our research.

During the semi-structured in-depth interviews, patients were asked questions about how they had made the decision to undergo transplant in relation to their personal circumstances and interactions with health professionals and members of their social network. Interviews were thematically analysed by the first two authors with a focus on information-giving, interpersonal relationships and the lived experience of transplant. Following immersion in the data via re-reading of transcripts and discussion with the broader research team, the first two authors developed a broad coding framework and used constant comparison to define, strengthen, collapse and expand different themes. The data presented in this paper focuses on a subset of these themes regarding how patients assimilated the information they needed to initially consent to proceed with the transplant and how nurses supported their ongoing consent and compliance over the lengthy transplant journey. All participant names and quoted names are pseudonyms.

Findings

Patients and health professionals alike described information about the transplant – including procedures, side effects, rigours

of transplant – as complex. This complexity was due to not only the large volume of information that patients were given access to – both by health professionals and information they found themselves via the internet – but also the unpredictability and variability of possible effects. These aspects meant that information provision was an ongoing activity achieved through multiple interactions with various health professionals over the course of the transplant. In this way, BMT provides a clear example of how consent needs to be viewed as an ongoing process rather than a static event at one point in time. For example, in their interviews, the nurses reflected on the informational complexity in terms of how challenging it was for patients to understand:

I think the whole area of transplantation is just so complex that even all of us have difficulty understanding everything that's going on, so it would be so difficult for a patient who just hasn't got the medical background or a certain level of education to understand everything that happens, or everything that could possibly happen – Kathleen, nurse.

Over the course of the transplant, patients and their families accessed information about the procedure during consultations and interactions with a variety of health professionals and from printed resources, including the internet and a book called *Allogeneic bone marrow transplant: a patients' guide* written by transplant doctors, nursing and allied health professionals and published by the Bone Marrow Transplant Network New South Wales²⁵. The BMT Network book provided an easy reference for patients and their families to address certain issues and questions that arose between their hospital visits. It contained detailed information about transplant preparation, donor searching, stem cell donation, transplant procedures, complications, nutrition, life after BMT, emotional impacts of BMT, social relationships, and practical issues including finances, accommodation and transport. Accessed internet resources included websites recommended by the relevant bodies such as the Leukaemia Foundation, the Cancer Council NSW and government departments. These websites provided further information about transplant procedures, emotional aspects of transplant and family relationships, accommodation, and financial services. Patients also accessed blogs written by transplant survivors.

Nurses recognised patients' different information preferences and needs, as well as how challenging the nature and volume of information about BMT was:

Some patients will say quite specifically "Don't tell me about it – I don't wanna know, I just wanna get through each day and then get out'a here" – Eva, nurse.

Patients don't want a lot of information, I mean what they want is to be cured... occasionally patients have said "... can't you just put me to sleep and wake me when it's all over?" – Kathleen, nurse.

This was confirmed by patients who articulated how the volume and complexity of the available information and their fluctuating vulnerable state meant that they were often overwhelmed by the information:

I was just so sick and I just blocked things out. I just couldn't, I couldn't take it all in, they just sort of [provide the information] holus bolus and it was just too much, too much information on top of everything – Elizabeth, patient.

Uh, well, actually, I felt quite involved [in decision-making] and I think that was to do with the staff because they [nurses] were always explaining everything, and if there was something that wasn't explained... then you know I would ask and... it would be explained to me – Claire, patient.

Patients often relied upon nurses to translate information into lay terms and to evaluate the relevance of this information for their specific transplant journey. Although it was often the case that patients had only one consultation with the transplant haematologist before proceeding to transplant, many of them also attended a hospital-hosted information day. At the information day, presentations were given by various health professionals from the BMT team – including a transplant haematologist, transplant coordinator, clinical nurse consultants, ward nurses, psychologist, dental specialist and social worker – and often a BMT survivor who described their own transplant experience. The professionals presented information about transplant procedures, complications, infection control and self-care. Emotional and practical implications of the transplant for patients and their family members were also discussed.

Patients emphasised how attending such a day helped them to understand information about the transplant they had received from the BMT book and their consultations, and the way the presentations provided content knowledge and reassurance:

The education session was good. I think the book and the education session worked well together. [The information day taught me] to be not so scared by the book. No because the book – if you read – the book's very good... I think it's really well written and it's really good on having a lot of, um, psycho-social aspects and talking about emotional support as well as the medical side of it. But if you just looked and read, the scariest chapter is the complications of bone marrow transplant. And that's quite scary for anyone to read and I think that when you go to the education session what the doctors then do, is um, clarify that. They clarify it and they sort of start saying "oh, some people will get this, a few people get this, this is pretty rare, this is pretty common." Rather than just having the complications, and the book doesn't quite have that finesse to it that a doctor can do in the education session. So you actually come away with a feeling of "oh, that isn't that bad, we found out there's these three bad things to worry about and the rest we don't have to worry about so much" – William, patient.

Nurses fulfilled roles as both transplant coordinators and ward nurses in the BMT setting. This led to them having more sustained interactions with patients over the course of their treatment where they provided information to patients more frequently than the doctors. This ongoing information support over the prolonged course of the BMT played a significant role in keeping the patient informed about what was happening and why:

I ask a few questions along the way... they fill me in on what was needed to be known... and I'm learning bits and pieces as I travel through. Sometimes I understand, sometimes I don't – Quincy, patient.

I would rather they come in and say "this is what's going to happen next" – that way I can sorta understand – Mia, patient.

This ongoing provision of information not only ensured that the patients' consent remained valid throughout the transplantation period, but it also provided them with reassurance that what they were experiencing was to be expected:

The only things that I ever needed to know was if something – if I didn't feel well, why didn't I feel well? – Edward, patient.

Nurses' role was also seen as ongoing and not restricted to specific consultation times as they had greater opportunities for more informal and accessible information provision with patients. The more frequent contact with patients led to more ad-hoc questioning from patients over the course of the BMT procedure. This information provision often occurred during interactions with nurses delivering clinical care rather than being a separate designated task.

Discussion

Information about BMT is enormously complex, and health professionals need to consider patients' informational needs and preferences when communicating with them about the procedure²⁶. Additional complexity is present as patients' informational needs may often change throughout the course of their treatment²⁷ as their physical, cognitive and emotional vulnerability fluctuates.

Acknowledging and accounting for this complexity within information provision activities was found to be a challenging task in our study. Whilst becoming informed about transplant procedures and side effects through printed and internet-based resources was viewed as important by patients, these resources only became useful when presented by or discussed with health professionals. These interactions helped patients to understand the importance of different aspects of the BMT and manage the volume of available information by having it interpreted for them and their questions responded to over time.

The need for discussion, interpretation and repeated presentation of information over the long course of BMT identifiably

positions this task within the remit of nurses given their unique role in supporting patients' physical and emotional needs while concurrently providing clinical care over an extended period of time. In identifying the role of nurses in this process, we emphasise how these professionals complement other members of the transplant team by using their unique positions and skills to ensure adequate information is both provided and understood by the patient – to the best of their ability – over the course of the transplant. We also emphasise that the importance of the process and practice of information provision is equally as important to consider as the content of that information in achieving ongoing consent.

BMT is a complex and complicated procedure that cannot, and should not, be viewed solely in terms of the biomedical stages in the process. Almost all patients who undergo BMT experience a wide range of psychological and psychosocial disruption to their lives, beginning during their in-patient admission. It is during this time that the patients invariably rely on the nurses to remind them of relevant information about the next phase in the transplant trajectory.

The literature has identified nurses' role in informed consent processes to include that of communicators, information givers and advocates^{28,29}. Our findings support these claims and highlight the need for further research on these roles in different clinical contexts.

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