Blood transfusion from the recipient’s perspective

MARY FITZGERALD MN, PhD
Senior Lecturer, Department of Clinical Nursing, The University of Adelaide, Adelaide 5005, South Australia

BRENT HODGKINSON BSc, MSc
Research Officer, Blood Transfusion and Intravenous Cannulation Service, Department of Clinical Nursing, University of Adelaide, Adelaide 5005, South Australia

DAWN THORP BSN, RN
Clinical Nurse Consultant, Royal Adelaide Hospital, Adelaide 5000, South Australia

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Summary

- This paper reports on an interpretative research study that set out to develop a rich description of patients’ experiences of the process of preparing for and receiving a blood transfusion.
- The themes of information-giving and receiving; reactions, both physical and emotional; and the care and treatment participants received through the experience are presented.

Keywords: blood transfusion, information-giving, phenomenology.

Introduction

With the current expansion in media information, the general public is exposed to a range of medical and lay information regarding the benefits and risks associated with blood transfusion. In view of the changes in the blood transfusion process, it is inevitable that the experience has also changed for patients. It is timely to consider the experience of people receiving transfusions, and to acknowledge the importance of their perspective when considering the most efficient and effective means of delivering nursing care to people receiving a blood transfusion.

Nurses are warned to view blood transfusion responsibilities as more than the technique of checking numbers and hanging the product (McGuire & Hayden, 1990). They need to be able to identify the nursing required to care for patients receiving a blood transfusion so that they can develop their skills and extend their knowledge in the area to the patients’ advantage. A grasp of the fundamentals of therapies as they are experienced by patients is a prudent foundation for the development of propositions regarding nursing practice (Kestenbaum, 1982).

In September 1996 a large metropolitan teaching hospital in Australia established the Blood Transfusion and Intravenous Cannulation Service (BTICS) in response to requests from the Transfusion Committee and hospital management. The terms of reference for the service were to examine:

1. The appropriateness of transfusions;
2. The methods by which transfusions are administered and monitored.

To date, the service has provided audits of transfusion practice in six service areas of the hospital and theatres.
The first report of this work was presented to the Transfusion Committee in 1997 (Pearson et al., 1997). Data were collected using a questionnaire consisting of 103 possible questions and 236 possible responses, and a range of information and recommendations regarding medical and nursing practice was presented to the Transfusion Committee (Hodgkinson et al., 1990). Besides questions that generated quantitative data, the questionnaire included a number of items requiring responses from patients regarding how they felt and what they understood about their blood transfusion. These items only required short answers and revealed vague feelings of being ‘OK’ or ‘not too bad’ and little evidence regarding how much individuals understood about the whole process. The team concluded that this was an area that required expansion and examination in order better to understand the patients’ perspective.

In order to look at the patients’ experiences in more depth, and thereby complement the factual data we were collecting regarding practices, a phenomenological study was undertaken. Qualitative data were collected by interviewing 19 patients following a blood transfusion. The study was funded by a small internal grant from the Faculty of Medicine. This paper is a report of the research.

**Literature review**

Blood transfusion is a standard therapy for the management of people who have undergone trauma (major surgery, burns, road traffic accidents and other accidents), who are receiving therapy for cancer, or who have haemophilia or other clotting disorders. Conteras (1992) makes the point that, if it were not for the ready availability of blood and blood products for transfusion, such recent medical advances as complicated cardiac surgery, bone marrow transplantation and aggressive chemotherapy could not be offered to patients.

Exhaustive literature reviews are not mandatory before the commencement of phenomenological studies (Morse, 1994), and this search was done to establish what nursing literature there was and how much nursing research, particularly similar studies to this one, had been undertaken (Holloway & Wheeler, 1996). A search of CINAHL and Medline from 1984 found 208 references using the keywords ‘Blood transfusion’ and ‘Blood transfusion and research’ in their titles for CINAHL and ‘Blood transfusion’, ‘Blood Transfusion & Nursing’ and ‘Blood transfusion and nursing and research’ in their titles for Medline. We concluded that literature regarding the nursing care of patients undergoing blood transfusion has focused on safety and ethics. This includes informed consent for the treatment, the checking procedure, delivery of the blood as prescribed and complications which may arise during the transfusion (Bradbury & Cruickshank, 1995; Caroll, 1995; Glover & Powell, 1995; Roach, 1995; Tranter, 1995). Medical advances have concentrated on immunohaematological complications of transfusion, prevention of transmission of infection by transfusion and the appropriate use of blood components. These developments have led to changes in the way blood is collected, the ways it can be prepared for transfusion, transfusion equipment, storage times and its use in the supportive management of critically ill patients (Conteras, 1992).

While there is some nursing literature surrounding the field of blood and blood product transfusion (referred to above) there is an overall paucity of published nursing research. What research there is concentrates on technique rather than patients’ experiences. For example, there is a study to evaluate the transfusion practices of nurses (Fruchart et al., 1997) and other research that examines the effect that certain parts of the infusion apparatus have on the quality and survival of cells (Norville et al., 1994; Prichard et al., 1994). There is also work to ascertain the difference between estimated vs. measured volume of packed cell units (Ellstrom, 1991). Some researchers have considered the availability of certain procedures such as Murdock & Roberson’s (1993) survey to determine autotransfusion system availability and use. Sciortino et al. (1993) include patients’ perceptions in their survey to ascertain the efficacy of administering blood transfusions at home to terminally ill cancer patients but this study only tentatively speculates that generally patients have a positive psychological benefit from receiving a blood transfusion. A number of papers examine the ethics surrounding the transfusion of blood and blood products to people with religious objections to it (Briggs, 1915; Nussbaum et al., 1994; Caroll, 1995). However, these papers usually consider particular cases and moral theories in general rather than research findings.

While it is undeniable that people have a right to information regarding all aspects of blood and blood transfusion products, it is pertinent to inquire how this information affects recipients. Writing anecdotally in 1991, a nurse describes the psychological discomfort she felt when receiving a blood transfusion and indeed the worry which persisted for some time afterwards. She acknowledges that having more information increased her state of worry (Kaberry, 1991). We have no evidence on which to judge the impact that increased information regarding the risks and benefits of blood transfusion has on patients’ peace of mind or their feelings of control.

Purpose of the research

The purpose of the research was to explore the meaning of patients’ experiences of blood transfusion. The study describes common and unique areas of concern and comfort for people through the process of receiving a blood transfusion. The information generated in the study will help nurses to understand patients’ experiences and enable them to nurse more sensitively. The research aims were to:

1 Develop a rich description of patients’ experiences of the process of preparing for and receiving a blood transfusion;
2 Make this information available to nurses so that they can bring an enhanced understanding of patients’ perspectives to their nursing practice;
3 Use this information to generate shared meanings which can be identified as criteria to be incorporated in the development of a questionnaire for larger distribution.

The research question was ‘What does it mean for patients to be faced with and undergo the experience of a blood transfusion?’

Study design

The methodological approach to this research is interpretative phenomenology using the works of Thompson (1990), Benner (1994) and Taylor (1994). In line with the purpose of the research, to understand experience, this methodological approach allows researchers to reveal meanings concealed in everyday actions.

Hospital Ethics Committee approval was given for the study. In the application, the researchers provided for anonymity for participants; informed consent; confidentiality; the right to withdraw from the study at any time; and security of all records. The team collecting the data for BTICS were asked to identify patients from amongst the people they visited each day who would be suitable and willing to be interviewed and able to talk about their experiences. The inclusion criterion for the study was any person able and willing to describe in English their experience of receiving a blood transfusion. There are no fixed rules about the required number of participants in a phenomenological study. Benner (1994) concedes that practical issues such as size of the study and amount of time available are considerations. We planned to interview 20 people (one person agreed to participate but, when visited at home, was too ill to do so) on the basis that this would provide a great deal of data from which to generate some local understanding of the phenomenon. A list of the participants is given in Table 1.

Table 1 Demographic data

<table>
<thead>
<tr>
<th>Age range</th>
<th>No of participants</th>
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<tr>
<td>21–30</td>
<td>3</td>
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<tr>
<td>31–40</td>
<td>1</td>
</tr>
<tr>
<td>41–50</td>
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<td>51–60</td>
<td>6</td>
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<td>61–70</td>
<td>2</td>
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<tr>
<td>71–80</td>
<td>3</td>
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<tr>
<td>81–90</td>
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<table>
<thead>
<tr>
<th>Gender</th>
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</thead>
<tbody>
<tr>
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</tr>
<tr>
<td>Females</td>
<td>5</td>
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<table>
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<tr>
<th>Diagnosis</th>
<th>No of participants</th>
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<tr>
<td>Cancer:</td>
<td></td>
</tr>
<tr>
<td>Haematological</td>
<td>2</td>
</tr>
<tr>
<td>Localized</td>
<td>4</td>
</tr>
<tr>
<td>Clotting disorders:</td>
<td></td>
</tr>
<tr>
<td>Haemophilia</td>
<td>1</td>
</tr>
<tr>
<td>Von Willebrand’s (planned surgery)</td>
<td>1</td>
</tr>
<tr>
<td>Organ failure:</td>
<td></td>
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<tr>
<td>Liver failure</td>
<td>1</td>
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<tr>
<td>Renal failure</td>
<td>1</td>
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<td>Emergency:</td>
<td></td>
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<tr>
<td>GI bleed</td>
<td>2</td>
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<tr>
<td>Ruptured spleen</td>
<td>1</td>
</tr>
<tr>
<td>Surgery:</td>
<td></td>
</tr>
<tr>
<td>Orthopaedic planned and trauma</td>
<td>4</td>
</tr>
<tr>
<td>Cardiac</td>
<td>1</td>
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<tr>
<td>Urological</td>
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</tbody>
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All interviews were conducted at the participants’ convenience by one researcher. Interviews ranged from 15 to 30 min. Participants were asked to talk about the experience of having a blood transfusion from the time they were first told about it.

All recordings were transcribed verbatim. Transcripts were read while the tapes were played in order for the principal investigator to check for accuracy and to ensure that no identifying markers had been left in. Raw data were then loaded into the computer program NUDIST (Richards et al., 1992).

As a first part of data analysis, descriptive case studies were written based on the transcription of each individual participant’s interview. The transcriptions were coded line by line, with the participants coded from A to S. Each line of the interview was numbered, e.g. A:35 = participant A, line 35. A cross-sectional analysis was then made of all transcriptions, identifying concepts which were later clustered into themes. After analysis was completed the themes were developed for presentation by writing and incorporating reference to individuals’ experiences, extant literature and the experience of the clinician in the team.

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This interpretation of the data was undertaken bearing in mind the interpretative process outlined in Table 2.

The broad themes that were developed to arrange participants’ experiences for the purpose of representing the research were as follows:

1 Information;
2 Reactions;
3 Treatment and care.

**INFORMATION**

The information that patients received dominated the interviews. Data revealed that great store was set on what participants reported they had been told by both doctors and nurses. In many instances they recalled verbatim what was said by the doctor or nurse. Information was coded in three main ways:

1 Information that the patients received from staff, both nurses and doctors;
2 Information that was given to staff, both nurses and doctors;
3 Assimilation and understanding of the information.

Medical staff were usually the first to tell patients that they were to have a transfusion. Some emergency patients who had no time for preparation could not remember being told that they would have a transfusion but everyone else could remember clearly. The reason provided for giving a transfusion is reported typically as ‘...because my blood was very low at that stage ...’ (A:35). Some people were expecting the transfusion because they were well attuned to their disease and knew the time was coming for another transfusion. These people were able to cite their blood results and view the information as just another part of the overall picture of their disease and its treatment. It is obvious that some of the patients knew their doctors quite well and talked to them in a familiar half-joking way: ‘... he just came in and said to me, “I just know you are going to hate my guts, Mrs Smith, but I’ve got to give you a blood transfusion”’ (D:10–12).

The doctors’ explanations usually tended to be brief and there were several examples of the patients’ excusing briefness because staff were busy or stressed:

The anaesthetist I had that day didn’t seem too keen going into a lot of details ... having never had an operation umm I guess I would have liked to have a bit more time and a bit more discussion ... it might have been a difficult day [for him] He’d had a difficult patient before me apparently ... so I think he was a bit annoyed by the time he saw me. (N:326–343)

Nurses explained things as they were going along, which was reassuring for participants. However, nurses tended to talk about relatively ‘safe’ subjects such as reiterating what doctors had said regarding the risk of infection, or talking about reactions that might occur during the transfusion and what was going to happen rather than inviting the person to talk about any concerns they might have had. Russon (1997) makes the point that an important part of informed consent is ‘deliberation’, that is, time for the patient to think about the decision to have treatment and to be able to discuss it with other health professionals. There is still a general reluctance on the part of patients to detain staff and ask them questions. Sometimes this is because questions do not occur to them straight away and at other times because they do not want to keep busy people talking to them:

... I just thought of it after he [the doctor] left ... but then the afternoon nurse came on, she came and spoke to me too ... and she went through some of the problems I might incur, like getting sweaty or getting a bit of the shakes ... (A:26–35)

From the transcriptions, it appears that people are given factual information, especially before the consent for a
Experiences of care

Blood transfusion is signed, but there is little opportunity for patients to discuss issues at length. Although there is a policy in the hospital that patients should sign a consent form for blood transfusion this was not always completed. In the BTICS study 58.5% of 365 patients had signed a consent form. There was nothing to suggest to us, either in this phenomenological study or the BTICS survey, that those who had signed a consent form were any better informed than those who had not.

Blood transfusion since the emergence of HIV has come to be perceived as a more risky procedure; while participants were told of these risks it did not appear that they were invited to express any worries regarding infection from transfusions. The Australian blood supply has been described as amongst the safest in the world (Pink & Isbister, 1996). Despite this, the attainment of a zero-risk blood supply is unrealistic. One report suggests that adding further tests, while preventing rare cases of transfusion-associated HIV, are not cost effective (AuBuchon et al., 1997). Thus the spectre of transfusion-transmitted infections will remain in the public awareness. Although numerous studies have been undertaken to determine the attitudes of people towards the donation of blood (Bartel et al., 1975; Leibrecht et al., 1976; Staallekker et al., 1980; Domen, 1995), few if any studies have been performed on perceptions of patients who are scheduled to or have received a blood transfusion. The reaction of participants in this study to the risk of infection will be covered in the next section of the paper: for now, it should be emphasized that they talked about the risk of infection and they received some information from doctors about it. This information ranged from an assurance that the screening was so good now that there was nothing to worry about, to an apparent contraposition recommending to a person undergoing planned surgery to donate her own blood so that she could avoid any risk of infection from donated blood from a stranger. The following extract is from a patient describing how she was advised to have autologous blood:

‘... he [the doctor] explained the reasons, you know, not just the risk of infection, of picking up infections and diseases or whatever from other people’s blood, he sort of said that’s one of the reasons. But another reason is that your body will just recover better from the operation with your own blood. (N:64–69)

These messages to the two different groups of recipients (autologous and allogenic) appear to be contradictory and confound the issue of the safety of donated blood. While it is tempting to suggest that there should be more conformity in information given (conformity that may be achieved by the use of printed or recorded information) the down-side of conformity is that people may not receive information related to their specific requirements. Kent (1996) makes this point referring health workers to psychological research that draws attention to important individual differences that determine the amount and type of information individuals require. A study by Arge (1993) to find the best way to give information to patients prior to a colonoscopy found that those who were shown a video had better post-test understanding than the control group who were informed by a physician. However, a related study (Arge et al., 1997) demonstrated that participants were more satisfied if they were able to talk to the doctor as well as see the video.

In 1991, the Australian National Health and Medical Research Council (NH & MRC 1991) published detailed guidelines for medical practitioners regarding information that should be given to patients in order for them to make decisions about their medical treatment and care. The document gives excellent advice to doctors (Chiarella, 1993), not only about what they should say, but how it should be done to ensure that the person has understood what they have been told. Precedents in law that have bound doctors to relay to patients all the material risks of a procedure, as in the case of Rogers v Ninth Whitaker (1992), may have made health care professionals concentrate on blanket delivery of information rather than the individual’s need for it. As Kaberry found (1991), knowledge of risks that are remote, as in the case of infection of blood, may just make the procedure uncomfortable.

Although information appears to flow from doctors and nurses, data gathered in this study contained little evidence of health professionals turning to patients for information. One striking exception to this was a long-term patient who was concerned about the maintenance of his precious venous access. His assertive stance had to turn to an aggressive one before he got the attention that he wanted. He was exasperated that he was not listened to or respected by a junior doctor and compares his treatment from that doctor and the consultant whose first action was to talk with him rather than argue:

I felt quite indignant that when [consultant’s name] had left specific instructions in my folder to be contacted, that I had to blow my cool.

[Name of consultant] came across and we discussed my treatments. I rated, I prioritized how, the order, I said, “[name of junior doctor] wants a gelco in, fine put a gelco in. But I think it’s reasonable to expect that it’s done right and done first time” because I was going to require another 10 days of treatment.

(S:131–143)
There were numerous instances of patients revealing that they did not understand what they had been told. Sometimes they would show that they had not grasped the full picture but this lack did not necessarily cause distress:

I've got to have a blood transfusion because of [pause] I don't know what you call it. In sum, I don't know what you call it. I haven't got enough blood. (R:52–55)

Yeah, and they put a, when they’ve finished they’ll put a small tube of neutralized sea water … (B:165–167)

Predictably, patients who had the best understanding were those who had experiences of blood transfusions in the past. They could talk of instances when they discussed their treatment with both nurses and doctors. As shown above, these knowledgeable patients were more likely to initiate conversations and to expect to be given reasonable explanations for care and treatment. Even though information regarding risk of infection worried recipients of allogenic blood they never indicated to researchers that they would have preferred not to have the information.

REACTIONS

Apart from the worry of infection from a blood transfusion, it was not seen to be an uncomfortable procedure. It is not viewed as particularly different from any other intravenous infusion. Reactions were coded in the following ways:

1 Emotional – feelings of fear, relaxation, appreciation, trust, resignation and anger;
2 Physical – being comfortable, feeling the same and experiencing side-effects.

Patients all talked about, or at least mentioned, the risk of HIV infection from the blood transfusion:

Yes because of AIDS and things like that. So that does make a person wary and it can’t be helped, like, I mean, everything is screened. It can’t be helped but it still gets through somewhere. (D:25–28)

Participants rationalized verbally, for example they said the risk was infinitesimal (‘one in a million’ was quoted four times), or that the consequence of not being transfused far outweighed the possibility of infection, or that it did not matter – ‘I’m dying anyway’ (L:351).

Guidelines (RAH, 1996) for the prescription of blood in the hospital encourage caution, and the BTICS study to date is showing compliance with the guidelines; thus participants are right. Their choice of whether or not to have a blood transfusion is limited by the severity of their physical condition.

Despite good reasons for going ahead with transfusion, fear of infection does linger:

I suppose anyway now I shouldn’t get AIDS but if they have AIDS in the blood, or if they have other diseases … Perhaps in the future the doctor will say, or some doctors might say, ‘This disease is from the blood you had in hospital’ I don’t know – but the only thing I am worried about, I was worried at the time and I’m worried now that it might be affecting me or it might give me another disease, I already suffer from angina and now I have an ulcer. (L:42–51)

The slight risk of infection is accepted as unavoidable and no blame is apportioned. Nor did the participants think that any more should or could be done to reassure them.

Some participants expressed a feeling of appreciation for the care and treatment they were receiving from health professionals and to people who have donated blood.

Because without people coming in and giving blood, well people like me would really be stuck. (E:145–147)

The only examples of dissatisfaction were from two participants, one who had not been listened to and one who had not been given enough information:

… the only thing would be, perhaps a bit more information, a bit more time and a bit more discussion … (N:379–389)

The blood transfusion often does not meet expectations in terms of a general improvement in wellbeing. People were told the blood would do them good but on the whole they did not feel better. A proportion of participants were feeling so ill from their medical condition and treatment that it was hard to discern any improvement.

TREATMENT AND CARE

This was the smallest of the main categories. Participants did not notice that their care was really any different from the usual. This coincides with information collected by BTICS that of 365 cases 70.4% reported that they were comfortable during the procedure.

The attention and care that doctors were seen to give was always at the beginning of the transfusion. They prescribed the transfusion and told the patient about it. They were not evident in participants’ descriptions of the transfusion itself.

The most important function of the nurse is seen as checking and hanging of blood. One patient said that she sneaked a look at the bag to make sure that it was the correct group. Some participants noted that nurses asked them questions during the transfusion to ensure they were not having a reaction to the blood. Besides these inquiries they
did not notice that they were having extra observations. Again this coincides with information gathered in the BTICS survey of blood transfusion practices. Although baseline observations were recorded prior to transfusion and 15 min after commencement, recordings during transfusions are erratic (Pearson et al., 1997). Roach (1995) reports similar practice for haematology/oncology patients during blood transfusion claiming that reactions are most likely to occur in the first 15 min of transfusion and that patients complain of side-effects before there is a change in vital signs. A systematic review is currently being undertaken regarding vital signs and practice information will be prepared by the Joanna Briggs Institute of Evidence Based Nursing and Midwifery, at the Royal Adelaide Hospital.

In terms of self-care, two participants, who were used to having transfusions, spoke of taking an interest in the timing of the blood in order to ensure that it got through in a reasonable time. They also looked at the cannula site and one reported pain there to a nurse but did not say what was done about it. A patient undergoing prolonged chemotherapy was most concerned about the state of his veins and took responsibility for ensuring that the transfusion kept dripping and that the cannula site was protected so that the vein could be used again. He has learned to do this from experience of numerous transfusions in the past. This participant had some of his treatment at home and his wife put in the intravenous cannula, but finding veins was becoming increasingly difficult for her. Part of his anxiety was in order to reduce the stress and inconvenience of his treatment at home. Assuming responsibility for one’s own care is stressful, and attention to his concerns and appropriate responses to his demands could have made this man’s experience of receiving a blood transfusion much less traumatic.

Patients receiving blood transfusions (see Table 1) were all acutely ill, either after surgery, receiving cancer therapy or emergency care, and for this reason they were likely to be given fairly intensive nursing care. This may be one of the reasons why they did not notice anything particularly special about the time they received the blood.

Conclusion

It seems that research which focuses on the subjective experience of patients usually generates results which are largely uncritical of both medical and nursing staff, and this study is no exception. Because blood transfusions are administered in response to a clear need, recipients appear to recognize that the attendant risks are outweighed by the advantages and thus they have few concerns in relation to its administration. In spite of this acceptance of blood transfusion as a mode of essential treatment, researchers in this study are still able to identify ways in which the experience could be enhanced. Knowing what is happening; why this is so; and what is to happen over time is central to the experience and the findings suggest that the timely provision of accurate, appropriate information are seen as important by those who receive blood. However, in this case, information-giving may not relieve stress or anxiety and, unless a way to completely eradicate the risk of infection from blood transfusions is found, it is inevitable that the process will induce some worry. Some time for the recipients of blood to deliberate on the information they are given and perhaps discuss the issues with nurses would be beneficial. It would also be helpful if doctors and nurses were given some advice regarding the information to be given to patients on this subject.

Overall, it is clear that having a blood transfusion is not as stressful an event as many others which occur during hospitalization. The procedure is not painful or particularly uncomfortable, the reason for the procedure is accepted, and the risks associated with it are often less dramatic than the outcomes of not receiving blood. However, there are some anxieties related to blood-borne diseases such as Hepatitis and HIV, and an awareness by nurses of the positive effects of information-giving and generic support to cope with and express worries is likely to improve the care of large numbers of people who receive blood in acute hospital settings.

Despite the availability of information in written form and verbally from doctors and nurses, some patients do not understand the facts. Health professionals would do well to pay attention to what the patient has understood and how they have received the information.

Patients who regularly receive transfusions are likely to be well informed and may wish to take some control during the process. Attention to their requests and an understanding of the stress they may be feeling would be appropriate.

While there was no attempt to generalize, the findings in this study illuminate some of the statistical information gained in the BTICS survey. Further work is planned to investigate the evidence for recording vital signs during a blood transfusion and in the area of informed consent for blood transfusion.

References


NH & MRC (1991) General guidelines for medical practitioners on providing information to patients., Canberra, Australia.


