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Consent to transfusion: patients' and healthcare professionals' attitudes towards the provision of blood transfusion information

R. Davis,[1] C. Vincent,[1] A. Sud,[2] S. Noel,[2] R. Moss,[3] M. Asgheddi,[1] I. Abdur-Rahman[1] & M. Murphy[2,4]

[1]*Department of Bio-Surgery and Surgical Technology, Clinical Safety Research Unit, Imperial College London, St. Mary's Hospital, London, United Kingdom,* [2]*Oxford University Hospitals, Headington, Oxford, United Kingdom,* [3]*Imperial College NHS Trust, St. Mary's Hospital, London, United Kingdom, and* [4]*NHS Blood & Transplant, National Blood Service, John Radcliffe Hospital, Oxford, United Kingdom*

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SUMMARY

Background: Patients should be informed about the risks and benefits of blood transfusion and their consent should be documented. However, this is not routinely practised in the UK, and there have been few studies to investigate patients' and healthcare professionals' attitudes towards this process.

Objectives: To investigate patients' and healthcare professionals' attitudes towards the information patients are provided with about transfusion and obtaining consent for transfusion.

Measures: A cross-sectional qualitative survey design was employed. Attitudes towards transfusion-related information and consenting to transfusion were assessed using a patient survey and healthcare professional survey.

Participants: One hundred and ten patients who had received a transfusion aged between 18 and 93 (60 males and 50 females) and 123 healthcare professionals (doctors, nurses and midwives) involved in administering transfusions.

Results: Sixty-one patients recalled consenting transfusion. The majority said they were just told they needed a transfusion ($N = 67$) and only 1 patient said a full discussion about the risks and the benefits of the transfusion took place. However, although 82 patients said they were satisfied with the information, 22 patients reported they would have liked to have been given more details. The majority of healthcare professionals ($N = 83$) felt that patients were often not given sufficient information about transfusion.

Conclusion: Greater efforts should be made to provide information to patients about the risks and benefits of blood transfusions. Future research should explore the most effective ways of delivering this information to patients in an appropriate and timely manner.

Key words: informed consent, patient attitudes, patient information.

Patient consent to transfusion is a topic that has stimulated much debate for a number of years (Williams, 1997; Farrell, 2010). There is a legal and ethical imperative that patients, if they are able to provide, should provide valid consent to any medical intervention prior to treatment. The General Medical Council have published guidance on consent stating that in order for consent to be valid the person providing consent must be competent, acting voluntarily, and be provided with sufficient information in order to make an informed decision (GMC, 2008). Providing patients with the right information at the right time is therefore a fundamental prerequisite to the patient being able to provide informed consent to transfusion. Information should be presented through open discussion with healthcare professionals; written information leaflets are also viewed as a valuable adjunct to aid understanding. However, despite the general agreement of the need to inform patients about the risks and benefits of transfusion and to document the consent process, this is not routinely practised in hospitals (Better Blood Transfusion, 2006, 2008, 2010; SaBTO, 2010).

In addition, but related to the issue of consent, it has also been suggested that sufficient information should be given to patients so that they can question the appropriateness of the blood transfusion (Davis *et al.*, 2011). The World Health Organisation has produced the 'Clinical use of blood handbook' which states that '*the appropriate use of blood and blood products means the transfusion of safe blood products only to treat a condition leading to significant morbidity or mortality that cannot be prevented by other means*' (WHO, 2002). Although transfusion is remarkably safe compared with other procedures, it does carry the risk of adverse reactions and transfusion-transmitted diseases. If it is not essential for a patient to receive blood they are given they

Correspondence: Rachel Davis, Department of Surgery and Technology, Clinical Safety Research Unit, Imperial College London, 10th floor, QEQM, St. Mary's Hospital, South Wharf Road, London, W2 1NY, United Kingdom.
Tel.: +44 020 3312 6243; fax: +44 020 7886 1810;
e-mail: rachel.davis@GRO-C

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are being exposed to unnecessary risk (WHO, 2002). However, in order for patients to question the appropriateness of the transfusion they need to be able and willing to do so and to possess the requisite knowledge about the procedure and their illness to understand what alternatives may be available.

In the UK, a number of patient information leaflets for both adults and children aimed at informing them of the risk and benefits of blood and blood component transfusion have been introduced (http://hospital.blood.co.uk/library/patient_information_aflets/leaflets/). The overarching objective of these efforts is to increase patient and public awareness about transfusion and to ensure that patients who are likely to receive a transfusion are well informed. To date little is known about the extent to which these leaflets are provided to patients. However, a recent audit showed that although such leaflets were readily available in NHS Trusts, many patients who had been given blood transfusions had not received them (Farrell, 2010). Research also suggests that prior to a transfusion many patients do not recall discussions regarding the risks and benefits of the procedure (Murphy *et al.*, 1997; Chan *et al.*, 2005), and that many patients would in fact welcome more information, particularly on these issues (Murphy *et al.*, 1997). In a study in 1997 only 31% of patients stated they had been given information before receiving their transfusion (Murphy *et al.*, 1997), and in a similar more recent study 59% of patients reported that the reason for a transfusion had been explained to them, just under 15% of which felt it was not adequately explained (Court *et al.*, 2011).

In the present study we aimed to build on the above findings by investigating patients' attitudes towards information they were provided with about transfusion and consenting to a transfusion. In addition, unlike the previous work in this area (Murphy *et al.*, 1997; Court *et al.*, 2011) we also examined healthcare professionals' attitudes towards the provision of transfusion-related information. By examining both the patient and the professional this allowed us to assess whether patients' requirement for information is being delivered by doctors and nurses. To the best of our knowledge this is the first study in the UK that has attempted to address both perspectives alongside one another.

METHODS

Design and materials

A cross-sectional qualitative design was employed using a patient survey and a healthcare professional survey. The patient survey assessed patients' attitudes towards: whether a discussion with the healthcare team about the transfusion took place; what information they were provided with; whether they were satisfied with the information; understanding of the need for transfusion; and recollection of consenting to the transfusion. The responses to the survey items were open-ended, so patients could provide as much or as little information as they wished.

The healthcare professional survey addressed similar issues to the patient survey including: whether they discussed the need for transfusion with all conscious patients who were transfused; what information they provide; whether they think patients are given sufficient information; and if they consent all patients. Consistent with the patient survey an open-ended response format was used.

Both surveys were piloted to ensure comprehension of survey items. Ethical approval for the project was obtained from the South Central – Oxford C Research Ethics Committee.

Participants

Data were collected from patients and healthcare professionals at Imperial College NHS Trust and Oxford University Hospitals NHS Trust. Patients were eligible to participate if they were able and willing to provide consent and had received a blood transfusion while conscious. To determine potential differences in attitudes regarding the need for information we focused on both patients who received a one-off transfusion (e.g. postoperatively on the ward) and those who were regular recipients of blood (e.g. ambulatory haematology patients). Data were collected on the hospital wards after the patient had been transfused (within 48 hours of receiving the transfusion). A member of the research team went through all the survey items with each patient individually and helped the patient to record their answers to the questions when required. All patients who met the inclusion criteria were approached and asked to participate in the study.

Healthcare professionals were eligible to participate if they were involved in the administering of blood transfusions. Data were collected from the same hospital wards as the patient data. In addition to this, some data (25%) were also collected during clinical meetings on blood transfusion safety. Healthcare professionals were given the surveys to complete themselves to provide their open-ended responses to the survey items. All healthcare professionals who met the inclusion criteria were approached and asked to participate in the study.

Both patients and healthcare professionals were given assurance that their answers were confidential and the results anonymised. Participant responses to items in the survey were transcribed verbatim and coded into emerging categories that were developed through general consensus within the research team.

RESULTS

Participant results

In total 110 patients and 123 healthcare professionals completed the surveys (response rates of 75% and 78% respectively). Tables 1 and 2 provide descriptive information on our study sample.

Participant responses in relation to information provision

Thirty (of 110) patients reported that no discussion at all about the need to have a transfusion took place; the majority of whom were patients with chronic illnesses who required regular transfusions ($N = 25$). Nine patients said a partial discussion took place (3 of whom were regularly transfused). Two patients said

Table 1. Patient characteristics

Characteristic	N
Sex	
Male	60
Female	50
Education	
No qualifications	31
College education	30
Undergraduate degree	11
Postgraduate degree	14
Vocational training	24
Employment	
Unemployed	14
Employed	23
Retired	60
Student	5
Registered disabled	6
Other	2
Age	18–93 (mean 60)
Prior experience of transfusion	
No	81
Yes	29
Race	
Caucasian	77
Non-Caucasian	33

Table 2. Healthcare professionals' characteristics

Characteristic	N
Profession	
Doctor	26
Nurse	74
Midwife	23
Sex	
Male	26
Female	97
Age	22–62 (mean 35)
Years qualified	0·5–39 (mean 7)

they could not remember if there was a discussion about transfusion with healthcare staff, and the overwhelming majority of the remaining patients (67 of 69), all but one of whom, were patients receiving a one-off transfusion, said they were just told they needed a transfusion.

'I was told I needed a transfusion, but very quickly, and there was no time for me to ask questions' (patient 4)

'I was informed about the need to transfuse... but I was just told I was bleeding but that was all' (patient 62)

Only one patient (of 68) said they were given the NHS leaflet 'receiving a blood transfusion' and only one patient said they fully discussed the transfusion with the doctor:

'I fully discussed why the transfusion was necessary and the risks and benefits but this was only because I kept asking questions' (patient 15)

However, despite these findings the majority of patients ($N = 82$) said they were satisfied with the information that was provided. In addition to this most patients ($N = 84$) said they understood why the transfusion was necessary, all of whom stating it was because they had either lost blood (mostly reported by those receiving one-off transfusions) or because their blood count was low (mostly reported by the regular recipients). However, 22 patients (all of whom were one-off transfusions) reported they would have liked to have been given more information:

'I was extremely concerned with the lack of information' (patient 100)

'I was not asked whether I wanted the transfusion, I was told...no discussion took place and I was not sure if there was an alternative' (patient 2)

The remaining patients felt that although they had not been provided with much information they were not dissatisfied with this because they did not feel they had a choice about the transfusion and just wanted to get better:

'I do not recall talking about the transfusion or completely understanding about it but all I remember thinking is that it was life and death and I just wanted to get better'. (patient 55)

'To me there was no choice, I had to have it...I did not want to become more ill' (patient 7)

Those patients who required a one-off transfusion appeared less satisfied with the information provided than those receiving regular transfusions.

When the same question was posed to healthcare professionals the vast majority (104/123) said they had a full discussion about the transfusion with every patient unless the patient was unconscious or confused:

'I would always discuss a transfusion with the patient unless of course the patient was not competent' (healthcare professional: doctor 6)

In addition, 21 (of 104) said they always gave the patient the NHS leaflet 'receiving a blood transfusion'

The remaining 19 respondents stated that they would not consider discussing the transfusion with a patient who was regularly transfused:

'I do not see the point in discussing a blood transfusion with a patient that comes in to see me at the day care unit – they know why they are here and do not need it explaining to them' (healthcare professional: nurse 41)

Interestingly, when healthcare professionals were asked if they felt patients were given sufficient information, the majority ($N = 83/123$) felt that *'more could be done'*, especially for patients receiving a one-off transfusion. The remaining healthcare professionals felt that patients were given a satisfactory level of information either *'most of the time'* or *'all of the time'*.

Participant responses in relation to consent

Sixty-one patients said they remembered consenting to the transfusion (55 verbally and 6 in written format). The remaining

patients said they could not remember ($N = 27$) or that consent did not take place ($N = 22$).

With regard to the healthcare professionals, all stated they would consent a patient (if they were competent); the extent to which they would document this varied depending on the patients' illness and understanding of why the transfusion was required. For patients who were regularly transfused, 'implied' consent was considered sufficient. Conversely, for patients who were receiving one-off transfusion the need to document the process was considered more important with a large number ($N = 62$) stating they would record this in the patient's medical records.

DISCUSSION

This study examined patients' and healthcare professionals' attitudes towards the information provided about blood transfusion and recollections of consenting to transfusion. Our findings show that although overall patients appear satisfied with the information they received, a considerable proportion do not recall discussing issues surrounding blood transfusion and expressed the desire for more information. In addition, just under half of patients questioned said they could not recall consenting to the transfusion. The majority of healthcare professionals stated that they discussed the need for the blood transfusion with patients, but the extent to which they practise this or document consent to the process appears largely influenced by whether the patient is a one-off recipient of blood or a patient who is regularly transfused. Two-thirds of healthcare professionals questioned felt that more information should be provided to patients, a finding that was particularly evident for those patients who had no prior experience of transfusion.

Our findings are similar to previous research that reported patients are not always given information prior to receiving a transfusion and that some were simply told they were going to receive blood (Murphy *et al.*, 1997; Court *et al.*, 2011) and that the decision was made by the physician (Weiss-Adams *et al.*, 2011). Our findings also indicate that in accordance with the existing research (Chan *et al.*, 2005) patients often have no or little recollection of the risks and benefits of the transfusion. Despite this, however, we also found that, in line with the existing research (Murphy *et al.*, 1997; Court *et al.*, 2011), many patients were satisfied with the amount of information provided. Our study adds to the existing body of research by also exploring the healthcare professionals' as well as the patients' attitudes towards transfusion-related information. To the best of our knowledge this is the first study to examine the perspectives of both the patient and the clinician in parallel.

Our study has several important implications. First and foremost is the issue of informed consent; this requires that a discussion with patients about the risk and benefits of the transfusion that is going to take place – our data suggest this was not always practised and that many patients cannot even recall consenting to the transfusion. Whether this is a failure on the part of the healthcare professional to provide this information or whether it is a failure on the part of the patient to recall this information remains unclear, although both factors are likely to play a role. What is clear however is that the current consent process is not meeting the standard set by the General Medical Council, and recently reinforced by SaBTO, for the informed patient in decision-making. Finding methods to effectively impart this information to patients in an appropriate and timely way is essential for the education of patients about why they might need a transfusion and what the alternatives may be. In addition, there is a huge variability both within and between hospitals in terms of discussing and documenting the consent to transfusion. Producing a standardised protocol for healthcare professionals to adhere to could be one way of tackling this problem. In recent years the possibility of asking patients to sign a separate written consent form for transfusion has been suggested, although more recently this has been dismissed because it only documents that the process took place and does not assess patient understanding (RCS, 2010).

In addition to the above, although practice is often constrained by time, the use of an information leaflet may also help to assist knowledge and in turn improve the process of consent (Hewitt *et al.*, 1998). However, only one patient in our study said they received a leaflet on receiving a blood transfusion, despite such resources being readily available in the hospital wards where the data were collected. This raises the important issue of dissemination. Providing accurate information to patients in a timely manner is a critical part of the process of consenting to a blood transfusion. Providing an information leaflets to patients could also help in part to address the apparent anxieties patients may have about receiving a transfusion. Many people overestimate the health risks involved in transfusion, in particular the likelihood of infection of blood-borne viruses (Lee *et al.*, 1997; Finucane *et al.*, 2000; Davenport, 2001; Moltzan *et al.*, 2001).

A further implication of our work is that healthcare professionals in our study appear to recognise that more information should be provided to patients, particularly those who have never been previously transfused. This finding is encouraging because it suggests that staff involved in delivering blood transfusions would be receptive to new initiatives aimed at educating patients about transfusions and empowering them to take on a more active role in their care. This is important because previous research suggests that patients who have received written information in addition to verbal discussion feel better informed and more comfortable with their decision to accept blood (Chan *et al.*, 2005).

Finally, despite many patients stating that a full discussion about the need for transfusion did not take place, many were still satisfied with the information provided. This in part could relate to the fact some patients when questioned viewed the transfusion as a matter of life and death. Given these patients felt they had no choice in whether they received the transfusion they may have viewed the provision of transfusion-related information as somewhat redundant. A further possible explanation is that a proportion of the patient population in our study were

patients who were regularly transfused; arguably these patients may feel they do not require any more information as they view themselves an 'expert patient' on the procedure. The fact that the patients who elicited the strongest preference for more information were patients with no prior experience of transfusion provides further support for this view. With this in mind healthcare professionals should be mindful of patients' individual needs and preferences and tailor care accordingly. Other factors such as patient demographics or the way that information is presented may also affect patients' informational needs. For example, research on patients' preferences for drug information leaflets suggests that age and level of education strongly influence patients' attitudes (Schwappach *et al.*, 2011). Research is required in the paradigm of transfusion-related information to determine whether a similar effect is displayed.

Our results should be interpreted with several caveats. First, the generalisability of this study may be limited since subjects consisted of patients from only two hospitals. It is likely that variation may exist with respect to information delivery and the practice of consent within different hospitals. The extent to which these findings can be replicated to a wider patient and healthcare professional population remains to be determined. Second, our findings were based on patients' recollections of consent and information provision. Given that there are inherent biases in memory that affect recall of information, future work should observe the discussion between healthcare professionals and patients immediately prior to the transfusion. Patients can then be questioned retrospectively about the information that was provided so that the validity of patients' recollections can be determined. Equally, healthcare professionals' responses could have been subject to social desirability biases. It is interesting to point out the difference between the number of patients who recalled receiving an information leaflet (1) and the number of healthcare professionals who stated they always give information leaflets to patients (21). This disparity indicates that at least some healthcare professionals could have responded in way they feel they should have, but not necessarily how they would act in practice. Observations of clinicians prior to administering transfusions would provide a useful way of assessing the accuracy of healthcare professional responses in our study.

It is clear that much more work is required in this area including both the way that information is tailored for patients and the way that it is delivered as both can have implications for the consent process. However, in order to determine the most efficient strategy of imparting transfusion-related information, the attitudes of patients need to be considered, and also those of healthcare professionals involved in their care. Data such as those provided in our study could be used to inform the implementation of shared decision making between patients and healthcare professionals. If a greater understanding is gained of how patients think and feel about transfusion-related information, there is greater opportunity to empower patients in making decisions not only about the use of blood but also about measures for blood avoidance such as optimisation of haemoglobin concentration in advance of surgery and other relevant medical interventions.

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CONFLICT OF INTEREST

The authors have no competing interests.

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