

## **Transfusion Risk and its perception in a wider context**

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### **Introduction**

In 1818 James Blundell carried out the first blood transfusions between humans . Over a 10 year period he transfused 11 patients, 5 of whom died.

Since then transfusion therapy has developed and is now one of the cornerstones of modern medical practice. The biology of transfusion has come under intense scientific scrutiny and continues to develop .These scientific developments form the sound basis of safer blood transfusion . A new perspective however has opened up in the past few years: the risks of transfusions, the assessment of such risks and the role of public perception of these risks for the future development of transfusion therapy.

An ESTM course in February 2000 in Brussels entitled “ Risk Perception and risk assessment in Transfusion medicine: how to achieve a sound scientific practice based on scientific truth “ (Ref 1) explored this topic in some depth . It became clear that communicating the risk of transfusion to the public and recipients and potential recipients of blood components and products is a complex issue and collaboration with disciplines outwith medicine is essential. Much work has been carried out in the social sciences in the field of communication, understanding and behaviour which the transfusion services of today would benefit from studying and applying.

This paper will focus on :

1. Current “professional“ knowledge (transfusion medicine specialists) of the risks of blood transfusion.
2. Attempts to convey the “professional“ knowledge to other professionals and lay public without distortion .
3. The options for risk reduction
4. The cost/benefit debate in transfusion therapy

### **Current professional knowledge of risks**

Knowledge of the risk of transfusion has been obtained, and continues to be learnt, from several different approaches - each with limitations. Perhaps the most informative are:

1. Follow-up of recipients of blood transfusion for any signs of complications.
2. Surveillance of the complications of blood transfusions.
3. Case histories.
4. Estimation of the number of expected complications based on modelling the variables that give rise to complications.

Follow-up of recipients has become an unproductive approach as the risks of transfusion have fallen. A recent study of the recipients of over 21,000 blood transfusions in England found no HIV, HBV, HCV or HTLV infections (Ref 2). Another disadvantage of this approach is that results are out of date as soon as transfusion practices change.

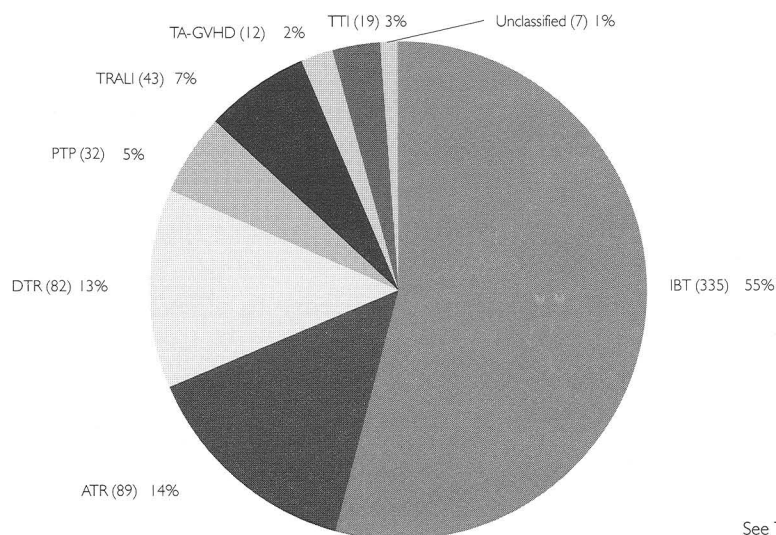
Many countries now have a system for monitoring complications of transfusion. In the UK we have a surveillance system called the Serious Hazards of Transfusion (SHOT) (Ref 3). Six-hundred and nineteen reports of complications of transfusion

were reported during the first three years of this surveillance system. The Table and Figure below show the nature, and relative frequency, of these reports.

**Table: Reports to SHOT, 1996-1999**

Nature of complication		Number	% of total
Incorrect blood transfused	IBT	335	55%
Acute transfusion reaction	ATR	89	14%
Delayed transfusion reaction	DTR	82	13%
Post-transfusion purpura	PTP	32	5%
Transfusion related acute lung injury	TRALI	43	7%
Transfusion associated graft versus host disease	TA-GVHD	12	2%
Transfusion transmitted infection	TTI	19	3%
Unclassified		7	1%
<b>Total</b>		<b>619</b>	<b>100%</b>

**Figure: Reports to SHOT, 1996-1999**



Twenty-six percent of these reports involved mortality of major morbidity associated with the transfusion complication. There was therefore 1 reported complication resulting in major morbidity or death for every 60,000 components issued for transfusion during these three years.

These data from the SHOT system, and similar data from other countries, provide evidence about how complications arise and present, and about the relative frequency of their presentation. However, under-recognition of complications associated with transfusion, and under-reporting usually mean the true number of complications is not known.

Either with or without a formalised reporting system, knowledge of the nature and causes of complications of transfusion is gained from the reporting of individual cases. Individual case histories are of particular importance when new complications arise.

Increasingly - and particularly for the risks of transfusion transmitted infection - estimations of the number of expected complications are made by modelling the variables that give rise to complications.

Such estimations have now been published from many countries (Ref 4). In England it has been estimated that with anti-HCV testing in place (but in the absence of nucleic acid testing), less than 1 in 500,000 transfusions may be infectious for HCV and less than 1 in 3 million donations may be infectious for HIV. Higher, but broadly similar, estimates have been made in other developed countries. Estimates from some developing countries are orders of magnitude greater.

These estimates require certain assumptions to be made that may cause error in the results, and the resulting range of probable results can be very wide. It is difficult to validate these estimates and so there is always uncertainty around their accuracy.

Some risks are unknown, for example, the risk of vCJD from blood transfusion in UK. The approaches described above have not yet produced reliable knowledge about this risk - which leaves transfusion medicine specialists without any accurate risk assessments.

## **Communication of this “professional knowledge“**

John Paling in “Putting medical risks into perspective“ (Ref 5) drew the distinction between data, information, knowledge and wisdom. Data are simply facts: transfusion services throughout the world abound in data collection. To take a simple example numbers of donations, sex of donors, age of donors etc. represent data.

Information is placing these facts in context: number of donations per population or per donor, movements in the numbers of donations with the day of the week or season etc.

Knowledge is bringing many fields of information together and, to continue with this particular example use of these donations and the adverse events associated with them related to other adverse events. We cannot have knowledge without information and we cannot have information without data.

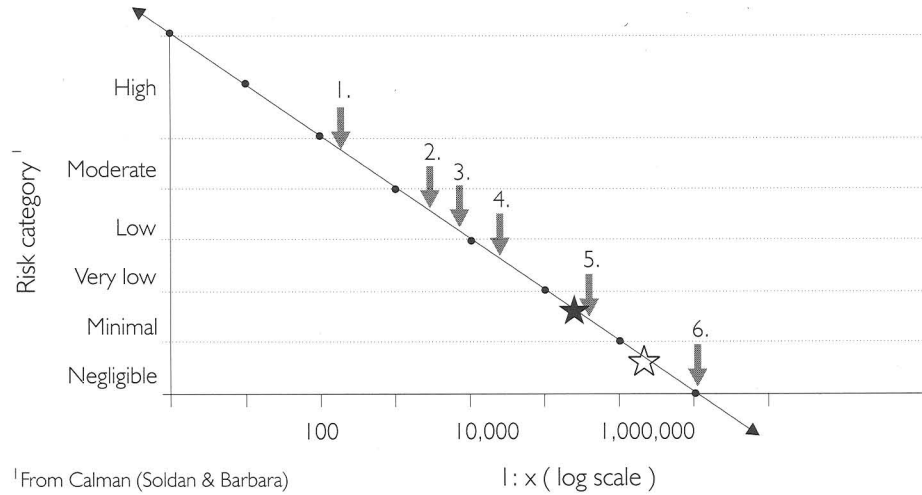
Wisdom, according to Paling, is non-context based understanding; a rare human trait.

Claudine Hossenlopp in communication about blood transfusion risks (Ref 6) points out that communication is always a two-way process. Otherwise it is merely a transfer of information. Communication involves checking the understanding of the recipient of the information. Risk communication is defined by Plough and Kirmsky (Ref 7)

as : experts intentionally conveying information about health or environment risks, obtained from scientists and technical experts, to a targeted audience of non-experts through designated channels.

Transfusion medicine specialists are used to talking of risks, such as 1 in 100, or 1 in 10,000 and seem to understand what this conveys. However it is clear that such facts mean little to the lay person and also the professional themselves when on the receiving end of a transfusion !.

There have been several attempts at communicating risk, not in numbers but pictorially. The SHOT pie chart is an example of such pictorial representation. Calman (Ref 8) published a risk line. We can use this to place the risk of transfusion in the context of other risks more familiar to people, as in the Figure below.



<sup>1</sup>From Calman (Soldan & Barbara)

Provisional estimates of infection in 1 donation:

- ☆ HIV
- ★ HCV

Death in 1yr due to:

- ↓ 1. Smoking 10 cigarettes / day
- ↓ 2. Influenza
- ↓ 3. Accident on road
- ↓ 4. Playing soccer
- ↓ 6. Hit by lightning

Paling has gone further and has developed a log diagram (Ref 5 and 9). The Paling Perspective Scale sets 0 at 1 in a million. This level has been chosen because it is the level below which all US government agencies have decided as a practical matter they will not regulate. Increasing and decreasing risks go logarithmically from this centre point, to the right and to the left respectively. Most of us live comfortably with a "home base" of risks of between 1 in 10,000 and 1 in 100,000, although whether the risks are taken by choice or inflicted on us makes a great difference to acceptability. These charts are under continuing development and may become a useful tool in medicine.

Studies of public perception of risks of transfusion or donation are rare. Politis (Ref 10) found that in 1994 only 58% of a sample of 1995 answered the question "can you catch AIDS by giving blood?" correctly ....

Finucane (Ref 11) collected data as part of a large national telephone survey of 1204 people in the US in 1997 and 1998. The results showed that a substantial proportion of the US population did not consider the US blood supply to be safe.

A seminar in London in October 2000 ( Transfusion 2020 ) explored this area further. The proceedings of this seminar will be published in Transfusion Medicine in early 2000.

### Options of risk reduction

The various options for risk reduction available to the transfusion services have been considered on an international level. (see diagram 1)

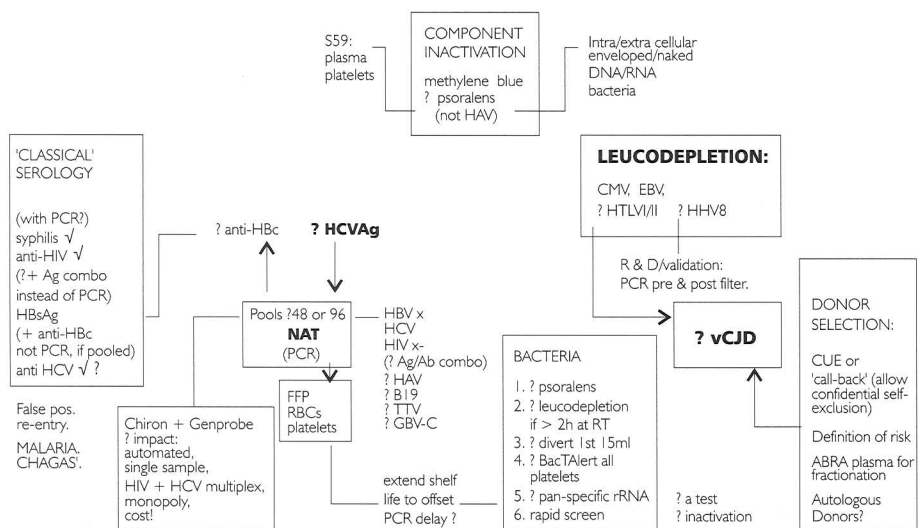
### Cost benefit debate in Transfusion Medicine

Transfusion Medicine specialists cannot escape becoming seriously involved in this debate in the 21st. Century. The extent of the debate throughout the transfusion chain were discussed by James and Barbara ( Ref 12 ) at an ESTM course in Castellanza in June 2000,

diagram 1

### Interacting Microbial Safety Options

1. Need to define priorities and rank them
2. How many interventions to reduce each risk?



The WHO is currently addressing these issues at a global level with a Consultation on Blood safety Policies from an international perspective and attempting to develop a framework which will allow policy decisions to be based on clear assessments of costs and benefit and be applicable world wide.

Aubuchon (ref 13) has analysed cost and benefit of various medical interventions in terms of cost for each year of life extended by the intervention (see diagram 2).

diagram 2

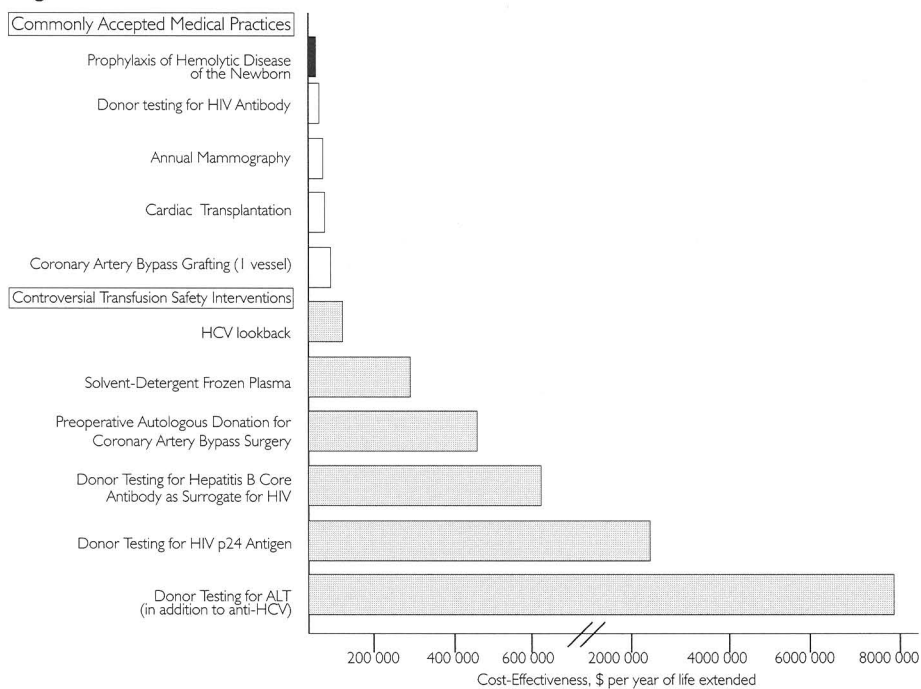


Figure 2. Comparison of cost-effectiveness of transfusion safety interventions (striped bars) and other medical practices (white bars) 27-31). ALT = alanine aminotransferase; anti-HCV = antibody to hepatitis C virus; HCV = hepatitis C virus.

(AuBuchon 1997, Ann Int Med 127, 904)

## Conclusion

Why does it matter to explore the public's perception of risk of blood transfusion in the 21st Century ?

Public acceptance of blood transfusion as a medical intervention is based on their perception of the risks involved, rather than the facts of the risk. It is clear that knowledge of the facts by the professionals is paramount, but this knowledge needs to be communicated to the public without distortion so they are able to make informed choices about their treatment. The future development of transfusion therapy, for example the development of blood substitutes depends on resources and anticipated demand, just as much as the development of commercial products. The demand comes from the public, and in this respect we must remember that the professionals are also part of the public.

Public acceptance of a certain level of risk of blood transfusion, if appropriately communicated may also influence the allocation of resources

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