Blood donors' preferences for blood donation for biomedical research

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Wiley
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Vera Raivola,1 Karoliina Snell,2 Satu Pastila,1 Ilpo Helén,3 and Jukka Partanen1

BACKGROUND: Increasing numbers of blood donors are recruited to participate in biomedical research. As blood services depend on voluntary donors, successful recruitment calls for a better understanding of donors’ expectations and attitudes toward the use of samples in research.

STUDY DESIGN AND METHODS: Sixty-one semistructured interviews were conducted with blood donors at eight Finnish Red Cross Blood Service donation sites in Finland. The 10- to 30-minute interviews included open-ended questions about donors’ views on blood donation for patients and for biomedical research. Central motives to donate blood for patients were identified against which views on research use were compared to see how these reflections differed.

RESULTS: Six central motives for donating blood for patients were identified among donors. The interviewees were, in general, willing to donate blood for research, but considered research donation more likely if it could be easily integrated into their usual blood donation habits. Biomedical research was perceived as important but its social benefits were more abstract than a direct help to patients.

CONCLUSIONS: Familiarity and reciprocity were key to the relationship between the blood service and blood donors. Donation for research introduces a new, more complex context to blood donation. Challenge to recognize concrete outcomes and benefits of donation may affect willingness to donate for research. Transparent communication of the role of the blood service in research and of the beneficiaries of the research is essential in maintaining trust. These results will help blood services in their planning to recruit blood donors for research projects.

ABBREVIATIONS: FRCBS = Finnish Red Cross Blood Service; R&D = research and development.

The increasing need for large, well-characterized cohorts of healthy individuals for modern biomedical research, such as genomics or phenomics studies, typically including tens or even hundreds of thousands of subjects,1,2 has posed the possibility of using blood services as an option for collecting samples and related data. The possibility to recontact blood donors for repeated sampling or asking for additional data has further increased interest in collecting large biobanks from blood donors. There is also a need to study more thoroughly the effects of blood donation on donor health.3,4 These studies require large research cohorts or biobanks of blood donor samples and data.

Volunteer blood donors have been assumed to have positive attitudes toward research donation; the
subject, however, has not been widely studied. Blood banks are usually well aware of the sensitive balance in the relationship they have with blood donors, in particular donors’ trust in ethically appropriate use of donated blood.\(^5\) To avoid unnecessary risks to disturb this balance, it is essential to understand motives for donation in general and the attitudes and expectations of donors toward donation for biomedical research. Considering the rich psychological\(^5,6\) and sociological\(^7-9\) literature on motives for donation for patient care, fewer studies have been conducted to clarify how blood donors view the use of their blood for research and what implications this has on their attitudes and willingness to donate.

According to the results of the Danish Blood Donor Study,\(^10\) research use of blood offers an opportunity to “extend the second gift of donation” into scientific knowledge and future patients. Other studies support blood donors’ flexibility and willingness to contribute in research,\(^11,12\) as well as provide a more complex picture.\(^13\)

The results of two studies from the United States showed that more than 90% of respondents agreed to allow the blood bank to store their “leftover” samples for biomedical research and felt that research was consistent with their mission to help others, but they wanted to be asked for permission or notified before the research use.\(^14,15\)

According to the Eurobarometer study that was not limited to blood donors,\(^16\) 60% of the Finnish respondents, compared to 60% in the entire European Union, would donate blood for patient care and 50%, compared to 33% in the entire European Union, for medical research. The results align with the results showing that the North European countries have a higher public willingness to donate for a biobank.\(^17\) These and other studies suggest blood donors are willing to participate in biomedical research, but the studies also note the need to better understand blood donors’ expectations and reasons for participation.\(^3\)

To develop a more detailed analysis of blood donors’ understanding of donation for biomedical research use and to complement the survey studies, we now report the results of qualitative, semistructured interviews. Similar methods have been used in other studies on blood donation.\(^18,19\) The research interview is a method widely used in the social sciences to construct systematic knowledge on cultural phenomena under study.\(^20\) The method is not quantitative and the results obtained do not represent a population sample; rather, the method identifies a set of topics raised or seen as important by the participants.

### MATERIALS AND METHODS

A total of 61 blood donors, five of whom deferred, participated in semistructured, open-ended interviews in six Finnish Red Cross Blood Service (FRCBS) centers located in the different parts of Finland and at two mobile drives in southern Finland. Recruitment followed selective sampling with the aim of ensuring that age (range, 18-67 years; mean, 42.3 years; median, 42 years) and sex (female: male ratio, 32:29) profiles approximately matched the profiles of blood donors at the FRCBS. Data collection continued until the accumulation of viewpoints was observed to reach saturation. Decidedly concise, 10- to 30-minute interviews took place while the donors were enjoying refreshments after blood donation. Study participation was clearly stated to be voluntary and anonymous. Interview questions (Table 1) were formulated to cover the main research themes. The exact form of the questions was partially based on feedback from pilot interviews of eight colleagues who were blood donors. The discussion order was chronological, beginning with the familiar then moving on to new scenarios. Interviews were in Finnish, apart from one conducted in English, and were recorded to be transcribed verbatim.

We started our content analysis using computer software (Atlas.ti, Version 7.0, Scientific Software Development GmbH). First, we systematically coded all interpretations of the reasons to donate, or refuse to donate, blood for patients or biomedical research. Authors VR and KS then organized manually coded accounts under descriptive categories we hereafter call “motives” in

<table>
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<tr>
<th>TABLE 1. Interview questions</th>
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<tr>
<td>Q1A: Why did you come to donate blood?</td>
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<tr>
<td>Q1B: How do you think donated blood is used?</td>
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<tr>
<td>Q1C: What impact do you hope your blood donation has?</td>
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<td>Q1D: How regularly do you donate blood?</td>
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<td>Q1E: What would make you decide to quit donating blood?</td>
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<tr>
<td>Q2A: In the Donor Information Pack it says that anonymous, surplus blood that is not required for the treatment of patients may be used for medical research, product development, and laboratory tests with FRCBS permission. What do you think about this?</td>
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<td>Q2B: Do you think you’d be ready to come, if Blood Service invited you to donate a sample of blood for scientific medical research on health and illnesses?</td>
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<td>Q2C: When you compare these two ways of using blood—for patients and for medical research—are they as important in your viewpoint (like 50%-50%)?</td>
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<tr>
<td>Q2D: If you decide to donate a blood sample to medical research, could you at the same time fill out a questionnaire about your lifestyle and health?</td>
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<tr>
<td>Q2E: Is there any type of research you think donors’ blood should not be used for?</td>
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blood use for patients and how these motives were reflected in research use. A new category was created if the coded passage of thought did not fit any existing themes. We compared the categories to determine how the motives to donate blood for patient care converged and differed from the reflections on donation for medical research.

**RESULTS**

The results of the interviews (n = 61), summarized as six key motives for donating for patients and the reflections and limitations of research use of blood, are shown in Table 2. The division highlights major differences in the reasoning by the donors regarding the purposes of the use of donated blood. It is of note that at the moment anonymous research use of the blood not needed for clinical use is allowed whereas an informed consent from the donor is required when personal data can be linked to the research sample.

<table>
<thead>
<tr>
<th>Motives for donating blood for patients</th>
<th>Donating blood for biomedical research</th>
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<tbody>
<tr>
<td>1) Helping patients</td>
<td>Helping medical research</td>
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<tr>
<td>2) Giving for a real need</td>
<td>General relevance of research</td>
</tr>
<tr>
<td>3) To contribute to the common good</td>
<td>Benefits for future society</td>
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<tr>
<td>4) Being a blood donor with a cooperative relationship with FRCBS</td>
<td>Being a research participant at the FRCBS</td>
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<tr>
<td>5) Giving a good feeling</td>
<td>Feel the importance in participation</td>
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<td>6) It is my habit</td>
<td>A small sample alongside blood donation</td>
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<table>
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<th>Reflections</th>
<th>Limitations</th>
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<tbody>
<tr>
<td>More distant than donating to patients</td>
<td>Difficult to understand the concrete relevance</td>
</tr>
<tr>
<td>Unclear who benefits and ethical contradictions</td>
<td>Transparency and trust are essential</td>
</tr>
<tr>
<td>Lack of concrete outcomes can lessen the feeling</td>
<td>Priority should still be giving blood for patients</td>
</tr>
</tbody>
</table>

Most donors, however, were only marginally interested in acquiring detailed information about how the blood was being processed and used. Instead, donors perceived the success of their mission to help depending on the cooperative relationship with the blood service (Table 2, Motive 4). Describing their role as blood donor, the interviewees often saw themselves handing over their rights and responsibility over the use of blood to the experts in the blood bank, whose first priority, they believed, was the safety of the donor and recipient. Without this trust, the motive of the donors would fail to be realized. The organization was expected to rely strongly on the support of volunteers, hence, to comply with their views on what are good and useful purposes of use for blood. The experiences of the donors supported the idea that they were cared for and that the organization seemed trustworthy in handling their donations:

Q1B/14F23: “[...] in Finland, the Blood Service is so trustworthy; this is safe for me and it is safe for the recipient, so I don't have that kind of worry. [...]”

Blood donation was perceived as an achievement that gave the blood donor a good feeling (Table 2, Motive 5) that encouraged them to continue donating blood despite the effort required. This experience was associated with an understanding that a blood donation as a collective effort may save or improve someone's life and contributes to the collective good.

Q1A/17M52: “... It's more about the certain feeling of empathy, [...] That's what makes it good, for the soul,
let’s put it in this way. […] It’s being part of something bigger than yourself.”

The interviewees saw blood donation as an easy meaningful routine, often referred to as “a good habit to help others” (Table 2, Motive 6). Many had learned the habit from colleagues, friends, or family.

**Blood donation to biomedical research**

In general, the interviewees had positive views regarding scientific research. Practically all of them considered it possible that they would donate a blood sample to help medical research (Table 2, Reflection 1); they felt that the donation may benefit the future common good (Table 2, Reflection 3). They expressed that, in the future, biomedical research could provide useful knowledge that would potentially help save and improve the lives of numerous people and that without research there would be no social progress. The interviewees expressed that they would be more inclined to participate in research if it could be organized by donating a small sample alongside the standard blood donation (Table 2, Reflection 6). Reservations were mainly practical and concerned additional time required, the amount of blood needed, and lack of relevant information.

Q2B/39F53: “Well, I guess I could come sometimes. It wouldn’t be that kind of basic reason to come, but if [the donation for research] could be part of it all, then why not. […] Here, they perform these [tests] for infectious diseases. So if they would just need another tube for research, I want to support this kind of activity, so why not.”

The idea of effectiveness, helping more with the same effort, appealed to many donors. Views on what is a tolerable extra effort depended on how relevant the cause was perceived to be. This raised questions regarding how much as blood donors they should understand the relevance of the research (Table 2, Reflection 2). The donors had varying views about what was a sufficient amount of prior information on the research projects, but most preferred to know more about the context, as Donor 28F39 described:

Q2B/28F39: “Hmm, it depends on the research and kind of how it would be described. It’s more of a faceless thing; what is it needed for? So I would want to know more about what is it used for and what’s being studied from it and that sort of things.”

Interviewees emphasized their limited understanding of research outcomes and practices. In their view, understanding the “population-level results” (as stated by Donor 30F33) and their impact on human well-being would require special expertise, compared to the immediate benefits of the blood products. Compared to the direct links that connect the blood donors to the patients, they saw the research system to be more distant (Table 2, Limitation 1) and complex. Research was a more abstract target for help and blood donors missed the concrete relevance of research and examples of future social benefits (Table 2, Limitations 2 and 3). The extensive time frame and complex organization of research were viewed to increase the risk that blood donors’ help would result in something unintended or unethical and it was not clear who will benefit from the donation (Table 2, Limitation 3).

Q2C/13F27: “[…] That it is concretely given to someone in need of help. In scientific research, the benefits, they come after a longer time period; it’s being researched and it can take years to realize the benefits. So yes, in a way it’s the time frame, that kind of immediate usefulness when it goes straight to the patient.”

Many, as Interviewee 13F27 above, indicated a preference to give priority to donate blood first to treat patients (Table 2, Limitation 6) and only then to be used for biomedical research.

All interviewees were presented with the option that research could take place in a commercial setting. While reactions to this varied, most interviewees were accepting of the concept. They acknowledged that the current society depends on private industry to translate research into health innovations. However, this fact did not fully resolve the discrepancy between commercial interests and their views regarding the ethics of voluntary blood donation. Participants asked what is a fair social distribution of the benefits gained from voluntary donations.

Q2A/32F31: “It would depend on what kind of product development the blood would go to. In a way, if it would go to a company, that would be like a strange situation […]12, because blood donors specifically donate their blood. I could perhaps donate to a company, but that would be a different situation. Because I assume I’m donating to people who need help.”

The interviewees expected their blood donations for research to serve the common good, that is, the research should tackle public health problems rather than commercially lucrative questions. Some interviewees pondered whether there could be a conflict of interest between research and development (R&D) and principles of reciprocity. However, interviewees usually assumed that they could rely on their blood bank, here the FRCBS, not “making business with their blood”; hence, blood donors
expected transparency and trust in the blood bank research relationship (Table 2, Limitation 4). To estimate whether they could trust their blood samples and health data to the hands of researchers, the donors referred to their views that the blood bank and regulatory institutions protect citizens and prevent unethical research. Interviewees expected that a research request coming from their blood bank should not be for anything “foolish” or “doubtful” but would adhere to the Red Cross values and reputation.

When blood was donated to treat patients, it was seen as extra with no returns to the donor. As biomedical research on blood samples may result in results useful to the donor, a new viewpoint on possible benefits to the self was noted. The majority of the interviewees appeared not to expect to receive any personal benefits for their contribution to research. For some donors there was no clear difference between scientific studies and routine blood testing. For them, gaining more information of their health status seemed an improvement to the current practice.

While the objective to help the future generations seemed valid, research was sometimes considered rather faceless. While blood donors endorsed biomedical research and appreciated its indispensable role in creating a healthier society, they recognized a possible challenge in selling research to blood donors and getting them to feel equally important to contribute to research in person (Table 2, Reflection 5).

Q2C/12F28: “[…] When you give your blood straight to help another human to support her survival, this might come closer to the motivation or reason why people come here. But if you think just a bit further, then certainly research is necessary especially for medical science and like human body it changes all the time … But from a marketing point of view it is more difficult to say: ‘Come donate blood for research.’ People might not see it the same way.”

DISCUSSION

The present study identified six major motives for blood donation for patient care. The motives were relatively similar to those reported in other studies.6,21-24 Many motives were related to the donor’s willingness to help and to create reciprocal welfare systems. These can be interpreted as solidarity,25 rather than an altruistic gift relationship.7 In addition, blood donation was seen as a habit or way to belong to the community of blood donors or blood bank.26 The picture was somewhat different when we asked about donation for research use. Blood donation for biomedical research clearly introduced new dimensions to the familiar social context of blood donation making, supporting the conclusions of the Nuffield Council report27 on tissue donation. In general the interviewees accepted the idea of donating for research use. Many had indeed adopted the viewpoint that they could extend the social and possibly personal value of blood donation if they invested in new scientific knowledge.10 The idea of effectiveness, helping more with the same effort, appealed to many donors. The preferred option for the interviewees appeared to be a small extra blood sample that could be taken to researchers without too much extra effort. However, the research use of blood was not viewed to be as straightforward as the standard blood donation. When donating blood for patients an immediate link to those who need the blood was clear but in the case of research donation the link to those using or benefiting from the sample was more abstract and the overall situation more complex; a similar concern was recently reported in a study among UK blood donors.19 The interviewees in this study understood that research donation potentially can help many but only in the future.

The use of blood for R&D activities, hence creating new business opportunities, introduced new levels to the discussion. While the relationship between the donor and the blood bank was seen as relatively simple and of mutual benefit when donating for patients, blood donation for product development raised the question of who may profit from the blood and by which terms. Questions concerned what is a fair social distribution of the benefits gained from voluntary donations and whether there could be a conflict of interest between R&D and principles of reciprocity. Taking blood from voluntary donors for the purpose of gaining private benefits would go against helping people in need. A few participants expressed concern that if the help will be used for private profit, the motives for donation may change and this might corrupt voluntarism. Yet, the donors expressed strong trust that the research, and obviously R&D as well, supported by their blood bank, in the present case the FRCBS, was ethically sustainable and important to the future of medicine. This trust is an extremely valuable asset that blood banks must be aware of and use with care when planning their research projects.

The present results and those by others18,28,29 suggest that the idea of gift does not comprehensively cover the current understanding of blood donation. When Titmuss7 wrote about the “gift of life,” he did not know about the coming developments, such as extensive research biobanks. His concept assumes that voluntary blood donors have no other interests or rights to the value derived from the blood gift beyond participation in a circle of common good. These values now take on a novel level in the form of valuable health data. The values now may become commercialized, contrary to Titmuss’ idea of the blood gift exchange as a social policy concept.30 The interviewees saw that the research promoted by FRCBS should
contribute to new information results in health benefits for future generations. According to the reciprocity norm, health benefits have been assumed to stay in the public realm, available for everyone in need and building a safer community life. However, it is equally realistic to suppose that the translation from bench to bedside requires commercialization. The blood donors also noted that research might result in useful information on donors’ personal health, which would bring a new form of reciprocity into blood donation. Time and social distance could also change the perceptions of donors regarding their reasons to donate. A study found that if a donation is perceived to have immediate positive outcomes, donors tend to prefer social benefits over benefits to the self, whereas increasing distance to the outcome shifted emphasis toward the latter. Some participants in this study also expressed their interest in research producing health screenings and other possibly useful results. Notably, some blood services have already successfully engaged blood donors to participate, blood banks using donors’ blood in cooperative research strategies. While gift continues to be a potent concept in the discourse on blood service policy, it fails to fully capture blood donors’ own accounts of the social contexts of their motives.

Acknowledging that some results might be particularly context-specific, the present study identified six motives to donate blood for patients. Compared to these motives, donation for biomedical research was recognized to be important and useful, but the connection to familiar relationships and social context was not as clear. The results of this study support the view that altruism—a concept often used to understand the blood donors’ motives—may not fit so well to describe donating blood for research. Research was considered a more abstract target for help due to the distance between the act of giving blood and concrete benefits for others. The acceptance and correct use of research samples was related to the strong trust the interviewees had for their blood bank. To avoid losing this trust and to motivate donors to participate, blood banks using donors’ blood in research and R&D should transparently communicate the purpose, beneficiaries, and conductors of research.

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