

The Meaning of Being a Living Kidney, Liver, or Stem Cell Donor—A Meta-Ethnography

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Background. Studies on living donors from the donors' perspective show that the donation process involves both positive and negative feelings involving vulnerability. Qualitative studies of living kidney, liver, and allogeneic hematopoietic stem cell donors have not previously been merged in the same analysis. Therefore, our aim was to synthesize current knowledge of these donors' experiences to deepen understanding of the meaning of being a living donor for the purpose of saving or extending someone's life.

Methods. The meta-ethnography steps presented by Noblit and Hare in 1988 were used. **Results.** Forty-one qualitative studies from 1968 to 2016 that fulfilled the inclusion criteria were analyzed. The studies comprised experiences of over 670 donors. The time since donation varied from 2 days to 29 years. A majority of the studies, 25 of 41, were on living kidney donors. The synthesis revealed that the essential meaning of being a donor is doing what one feels one has to do, involving 6 themes; A sense of responsibility, loneliness and abandonment, suffering, pride and gratitude, a sense of togetherness, and a life changing event. **Conclusions.** The main issue is *that* one donates irrespective of *what* one donates. The relationship to the recipient determines the motives for donation. The deeper insight into the donors' experiences provides implications for their psychological care.

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Living donation is well established and has been practiced successfully since transplantation became a clinical reality.¹ Today, a substantial number of kidney and liver transplantations are performed with living donors; globally 42% of kidney transplantations and 20% of liver transplantations.² All allogeneic hematopoietic stem cell transplantations (HSCT) are performed with live donors.³ As the medical and surgical donation procedures for kidney, liver, and stem cell donors differ, the short- and long-term medical risks are also different.^{4–8} However, irrespective of whether

the donation concerns an organ or stem cells, all living donors are in a similar situation, that is, they undergo a thorough medical assessment, are psychosocially evaluated, and eventually donate something from their body to someone with a life-threatening disease. Qualitative research deals with experiences, perceptions, and meaning making.⁹ When we understand the person's overall situation, including the social context, experiences, and feelings,¹⁰ it becomes possible to grasp the donor's personal understanding of donation, view it in terms of consequences for her/his daily life and interpret its meanings. Many studies show that donors are in a vulnerable position involving both positive and negative

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feelings,¹¹⁻¹³ which was reported as early as 1968 in the case of kidney donors.¹⁴ Negative donor experiences consist of, for example, anxiety, pain, and guilt, while positive experiences include happiness about being a match, an increased sense of self-esteem, and a closer relationship between the donor and the recipient.¹¹⁻¹³ We believe that the meaning of being a donor may emerge by synthesizing different living donor experiences with regard to what is donated. When healthcare professionals gain a thorough understanding of the person's overall situation, it is possible to tailor living donor programs in a person-centered manner. This meta-ethnography might provide a reasonable foundation. Thus, the aim of this meta-ethnography was to synthesize current knowledge of hematopoietic stem cell (HSC), kidney, and liver donors' experiences to deepen understanding of the meaning of being a living donor for the purpose of saving or extending someone's life.

MATERIALS AND METHODS

We followed the meta-ethnography steps described by Noblit and Hare.¹⁵ This methodology synthesizes interpretive research by comparing and translating the findings of qualitative studies into each other, thereby developing overarching metaphors leading to a new understanding. According to Noblit and Hare, "A meta-ethnography seeks to go beyond single accounts to reveal the analogies between the accounts" [15, p13]. The 7 steps in this method are described and presented in Table S1, SDC (<http://links.lww.com/TP/B520>). The "Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ" statement by Tong et al¹⁶ was served as a guide for reporting the stages in our synthesis of qualitative studies on living donors.

As the relationship between the recipient and the living donor has changed considerably over the years from exclusively blood related donors to anonymous donors, from this point onward, we will use the terminology for living organ donation used by Dor et al,¹⁷ that is, specified or unspecified living donation. Specified donation means that the donor and recipient are biologically or emotionally related, whereas unspecified donation is when the donor is anonymous to the recipient. Both specified and unspecified living donors are used for kidney, liver, and HSC transplantation.¹⁸⁻²⁷

Inclusion criteria for this synthesis were qualitative studies using interviews, focus groups or narrative data collection, performed after the donation, describing the experiences of being a specified or unspecified adult (≥ 18 years) living donor of a kidney, a piece of the liver or hematopoietic stem cells. Non-English language articles, studies performed before the donation, studies using structured surveys, reporting only quantitative data, and nonprimary research such as reviews and editorials were excluded. Studies of the same study sample with different aims were included in the analysis.

Literature Search

To gain an overview of studies of living donors' experiences we performed an initial literature search using appropriate key words in 3 electronic databases: PubMed, CINAHL, and PsychINFO. Thereafter, a comprehensive search strategy was used,²⁸ and the final key words were developed in collaboration with a health sciences librarian to identify qualitative studies that met the inclusion criteria. The searches were performed by combining different key words in the same 3

electronic databases as in the initial search (Table S2, SDC, <http://links.lww.com/TP/B520>). In addition, a manual search of the reference lists from the identified articles was conducted.

Data Abstraction and Synthesis

The 41 articles included were reviewed in several steps. The Critical Appraisal Skills Programme (CASP) was used for quality assessment.²⁹ All members of the research team appraised the articles and each article was independently assessed by 2 of the authors before the decision to include it was made.

All selected studies described experiences of being a living donor for the purpose of saving or extending someone's life. When the study selection was completed, data abstraction and synthesis began by continuing with the third of the 7 steps presented by Noblit and Hare.¹⁵ The result sections of the included studies were read; each study was read separately by 2 members of the research team, who also noted metaphors (step 3). Relevant descriptions of living donors' experiences that corresponded to the aim of our study were not always visible in the overarching themes and concepts reported in the studies due to their different aims, for example, psychosocial problems, quality of life issues, and coping strategies.³⁰⁻³² However, the result sections often contained rich descriptions of living donors' lived experience. The research team decided to search for both first- and second-order perspectives.³³ Accordingly, we included key metaphors as concepts, themes, and meaning units, as well as expressive quotations from the study participants (step 4). A data extraction template with columns was constructed, and each article was scrutinized independently by 2 researchers, who identified and juxtaposed the findings (both first- and second-order accounts) in the template. Four of the authors continued with the analysis (steps 4 and 5) by comparing and translating the extracted findings into each other. This process included searching for similarities and differences in the accounts.¹⁵ The content of the template was systematically compared with guarantee congruence and ensure that no important findings were left out of the subsequent analysis. Despite searching for contrasting metaphors in the extracted accounts, we found that they were seldom in opposition to each other but described similar experiences of being a living donor, irrespective of what was donated. To cite Noblit and Hare: "when ethnographies are about similar things they can be synthesized as reciprocal translations of each study into the others" [15, p 38]. Content with a similar meaning was then compared and grouped together (step 6). This was an iterative and inductive process where all researchers in the team worked in smaller groups. Several possible interpretations were considered and discussed, while preexisting concepts were created into new ones. Finally, consensus was achieved between all members of the research team on 6 themes that described a third-order perspective of the meaning of being a living donor that transcended the findings of the individual studies.

FINDINGS

Study Selection

The initial search yielded a total of 8997 articles. When using the comprehensive search strategy together with the manual search, 152 potentially relevant studies were identified

for screening, including one book³⁴ (see Figure 1). After exclusion of duplicates 148 titles and abstracts were reviewed and a further 60 studies excluded. When the remaining 88 were read an additional 47 were excluded. The reasons for exclusion in all steps of the selection process can be seen in Table S3, SDC (<http://links.lww.com/TP/B520>). The final number of articles in the meta-ethnography was 41 (Figure 1).

When using the CASP tool for quality assessment of the 41 selected articles we found that 17 contained no description of the relationship between the researcher and study participants, while 18 made no mention of ethical approval. However, the content of the articles was highly valuable, that is, they contained rich descriptions of the experiences of being a living donor for the purpose of saving or extending someone's life, thus no study was excluded on the basis of the CASP assessment (Table S4, SDC, <http://links.lww.com/TP/B520>).

Characteristics of the Studies

All studies (total n = 41) included in the synthesis were published between 1968 and 2016 and concerned adult living donors. The characteristics of the studies are presented in Table 1. Of the 41 studies, the majority (n = 37) were conducted in countries in the Western world. The most commonly used qualitative method was phenomenology (n = 11), and 3 studies used phenomenology combined with content analysis. Data were collected by individual interviews in all but 3 studies. The vast majority of the studies included kidney donors (n = 25). Specified donors' experiences are more frequently studied than those of unspecified donors (specified, n = 33; unspecified, n = 6; specified and unspecified, n = 2). In several of the articles, it was difficult to find information

about the individual characteristics of the donor and recipient, thus this information is not presented. The studies comprised more than 670 donors, although the sample size was not stated in all studies. There were slightly more women than men in the total sample of informants based on the studies in which the gender of the donor was reported. The time since donation varied greatly, both within and between studies (2 days to 29 years).

Synthesis of the Findings

The synthesis comprises 6 themes illustrating motives for donation, experiences of donation, and outcomes of being a living donor; *A sense of responsibility*, *Loneliness and abandonment*, *Suffering*, *Pride and gratitude*, *A sense of togetherness*, and *A life changing event*. As donation is multifaceted several of the themes are relevant to each individual donor during the whole donation process. A summary of the studies that support the themes is presented in Figure 2 and quotations illustrating the 6 themes can be found in Table 2.

THE THEMES

A Sense of Responsibility

When living donors first hear about the possibility of becoming a donor, the decision to donate can either be made quickly or as the result of a deliberate decision-making process, including weighing the pros and cons.^{31,37} Overall, the decision to become a live donor is characterized by a firm commitment and a sense of responsibility for the well-being of another person.^{14,30-32,34-70} Watching a loved one or significant other suffer from a life-threatening illness prepares

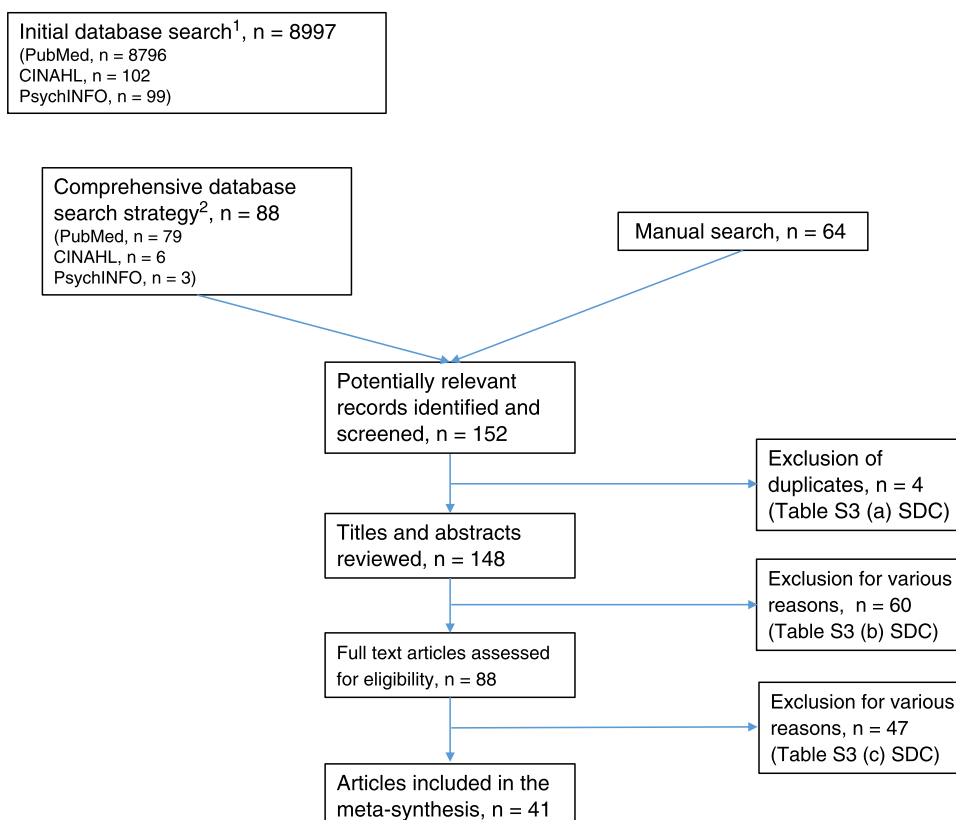


FIGURE 1. Flowchart literature search. Table S3, SDC, can be viewed at: <http://links.lww.com/TP/B520>.

TABLE 1.
Summary of the studies included in the meta-ethnography

Study ID	Country	Approach/method	Time since donation (range)	Sample size (n) sex	Donor type (kidney, liver, bone marrow/PBSC)	Classification of relationship with recipient
Fellner and Marshall, 1968 ¹⁴	USA	Qualitative analysis method not described Individual interviews	5 wk to 18 mo	n = 12; F = unknown, M = unknown	Kidney	Specified
Simmons et al, 1987 ²⁴	USA	Mixed methods (quant. & qual.) Qualitative analysis method not described Individual interviews	5 d and 1 y (predonation interviews not included in this synthesis)	n = unknown; F = unknown, M = unknown Interviews performed with > 200 families	Kidney	Specified
Adams-Leander 2011 ³⁵	USA	Interpretive phenomenology Individual interviews	<12 mo to >20 y	n = 8; F = 6, M = 2	Kidney	Specified
Agerskov et al 2016 ³⁶	Denmark	Phenomenological-hermeneutic Individual interviews	3 mo	n = 8; F = 5, M = 3	Kidney	Specified
Andersen et al 2005 ³⁷	Norway	Phenomenology Individual interviews	1 wk	n = 12; F = 7, M = 5	Kidney	Specified
Andersen et al 2007 ³⁸	Norway	Phenomenology Individual interviews	1 y	n = 12; F = 7, M = 5	Kidney	Specified
Brown et al 2008 (I) ³⁹	Canada	Phenomenology Individual interviews	4-29 y	n = 12; F = 4, M = 8	Kidney	Specified
Brown et al 2008 (II) ³⁰	Canada	Phenomenology Individual interviews	4-29 y	n = 12; F = 4, M = 8	Kidney	Specified
Crombie & Franklin, 2006 ⁴⁰	UK	Ethnographic fieldwork Individual interviews	2 d to 25 y	n = 20; F = 11, M = 9	Kidney	Specified
de Groot et al 2012 ⁴¹	The Netherlands	Mixed methods (quant. & qual.) Qualitative analysis method not described Focus group interviews	<1 y to > 5 y	n = 20; F = 13, M = 7	Kidney	Specified
Franklin et al 2003 ⁴²	UK	A) Phenomenology & Content analysis Individual interviews B) Ethnography	(A) 1-5 y; (B) 2 to 25 y	A) n = 20 F = 12 M = 8 B) n = 20; F = 11, M = 9	Kidney	Specified
Gill & Lowes, 2008 ⁴³	UK	Phenomenology Individual interviews	3-10 mo (predonation interviews not included in this synthesis)	n = 11; F = 6, M = 5	Kidney	Specified
Hajjamäe et al 2003 ⁴⁴	Sweden	Phenomenography Individual interviews	>3 y	n = 10; F = 4, M = 6	Kidney	Specified
Langenbach et al 2009 ⁴⁵	Germany	Content analysis based on Grounded Theory Individual interviews	1.7 to 3.1 y	n = 11; F = 7, M = 4	Kidney	Specified
O'Driscoll et al 2011 ⁴⁶	Australia	Mix methods (quant. & qual.) Thematic analysis Individual interviews	Unknown	n = 18; F = unknown, M = unknown	Kidney	Specified

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TABLE 1. (Continued)

Study ID	Country	Approach/method	Time since donation (range)	Sample size (n) sex	Donor type (kidney, liver, bone marrow/PBSC)	Classification of relationship with recipient
Pradel et al 2003 ⁴⁷	USA	Content analysis & Phenomenology Focus group interviews	A few months to 4 y	n = 9; F = 5, M = 4	Kidney	Specified
Sanner, 2005 ⁴⁸	Sweden	Narrative structuring Individual interviews	3 weeks	n = 39; F = 23, M = 16	Kidney	Specified
Ummel & Achille, 2016 ⁴⁹	Canada	Interpretive phenomenology Individual interviews	8-32 months	n = 5; F = 4 Unknown 1 (friend)	Kidney	Specified
Walsh, 2004 ⁵⁰	Northern Ireland	Phenomenology Individual interviews	unknown	n = 8; F = 3, M = 5	Kidney	Specified
Williams et al 2009 ⁵¹	Australia	Grounded theory Individual interviews	1-11 y	n = 18; F = 14, M = 4	Kidney	Specified
Zeiler et al 2010 ⁵²	Sweden	Narrative analysis Individual interviews	6-18 months	n = 6; F = 2, M = 4	Kidney	Specified
Clarke et al 2014 ⁵³	UK	Grounded theory Individual interviews	1-37 months	n = 14; F = 6, M = 8	Kidney	Unspecified
Tong et al 2012 ⁵⁴	New Zealand	Grounded theory and thematic analysis Individual interviews	5-147 months	n = 18; F = 11, M = 7	Kidney	Unspecified
Shaw, 2015 ⁵⁵	New Zealand	Thematic analysis Individual interviews	Unknown	n = 25; F = 18, M = 7	Kidney	Specified & Unspecified
Shaw & Bell, 2015 ⁵⁶	New Zealand	Thematic analysis Individual interviews	Unknown	n = 25; F = 18, M = 7	Kidney	Specified & Unspecified
Cabello and Smolowitz, 2008 ⁵⁷	USA	Phenomenology Individual interviews	7-16 months	n = 6; F = 5, M = 1	Liver	Specified
Crowley-Matoka et al 2004 ³¹	USA	Content analysis Individual interviews	3-10 y	n = 15; F = 11, M = 4	Liver	Specified
Forsberg et al 2004 ⁵⁸	Sweden	Phenomenology Individual interviews	12-72 months	n = 11; F = 2, M = 9	Liver	Specified
Kusakabe et al 2008 ⁵⁹	Japan	Content analysis Individual interviews	<1 y to > 4 y	n = 18; F = 8, M = 10	Liver	Specified
Nasr & Rehm, 2009 ⁶⁰	USA	Interpretive ethnography Individual interviews	≥1 y	n = 13; F = 8, M = 5	Liver	Specified
Weng et al 2012 ⁶¹	Taiwan	Content analysis & Phenomenology Individual interviews	1-6 months	n = 7; M = 7	Liver	Specified
Christopher, 2000 ⁶²	USA	Content analysis Individual interviews	Mean 9.25 months (no range described)	n = 12; F = 8, M = 4	HSC (bone marrow)	Specified
de Oliveira-Cardoso et al 2010 ⁶³	Brazil	Descriptive exploratory Individual interviews	Immediately after donation (predonation interviews not included in this synthesis)	n = 20; F = 9, M = 11	HSC (bone marrow)	Specified

Munzenberger et al 1999 ³²	France	Mixed methods (quant. & qual.) Qualitative analysis method not described Individual interviews	1 month	n = 11; F = 5, M = 6	HSC (PBSC)	Specified
Parmar et al 2003 ⁶⁴	Canada	Qualitative analysis not performed Narrative	12 y	n = 1; M = 1	HSC (bone marrow)	Specified
Pillay et al 2012 ⁶⁵	Australia	Mixed methods (quant. & qual.) Thematic analysis Individual interviews	0-3 y	n = 22; F = 9, M = 13	HSC (bone marrow or PBSC)	Specified
van Walraven et al 2012 ⁶⁶	The Netherlands	Phenomenology Individual interviews	0.4-5.0 y	n = 13; F = 6, M = 7	HSC (PBSC)	Specified
Butterworth et al, 1992 ⁶⁷	USA	Mixed methods (quant. & qual.) Qualitative analysis method not described Interviews	1 y	n = 50; F = unknown, M = unknown	HSC (bone marrow)	Unspecified
Holroyd and Molassiotis 2000 ⁶⁸	China	Content analysis Individual interviews	1-7 y	N = 37, F = 22, M = 15	HSC (bone marrow)	Unspecified
Simmons et al 1993 ⁶⁹	USA	Mixed methods (quant. & qual.) Qualitative analysis method not described Individual interviews	1 week and 1 y (predonation interviews not included in this synthesis)	n = 50; F = unknown, M = unknown	HSC (bone marrow)	Unspecified
Wanner et al 2009 ⁷⁰	Germany	Grounded theory Individual interviews	~4 weeks after receiving information about the death of recipient	n = 12; F = 3, M = 9	HSC (PBSC)	Unspecified
Year of publication: 1968-2016	Countries: USA, n = 10 Canada, n = 4 Sweden, n = 4 Australia, n = 3 New Zealand, n = 3 UK, n = 4 Germany, n = 2 Norway, n = 2 The Netherlands, n = 2 Denmark, n = 1 Brazil, n = 1 China, n = 1 France, n = 1 Japan, n = 1 Northern Ireland, n = 1 Taiwan, n = 1	Qualitative methods used: Content analysis, Ethnography, Grounded theory, Narrative, Phenomenography, Phenomenological-hermeneutic, Phenomenology, Thematic, Mixed qualitative methods, Mixed qualitative and quantitative methods Data collection: Interviews, n = 36 Telephone interviews, n = 2 Narrative, n = 1 Focus groups, n = 1 Interviews & telephone interviews, n = 1	Time since donation: 2 d to 29 y. Also predonation, n = 5 Unknown, n = 4	Sample size: n = 671 Study id: 34 n = unknown Sex: F = 287 M = 243 Study id: 14, 34, 46, 67, 69 sex = unknown	Donor type: Kidney, n = 25 Liver, n = 6 HSC (bone marrow or PBSC), n = 10	Relationship: Specified, n = 33 Unspecified, n = 6 Specified and unspecified, n = 2

F, female; M, male; PBSC, peripheral blood stem cell collection.

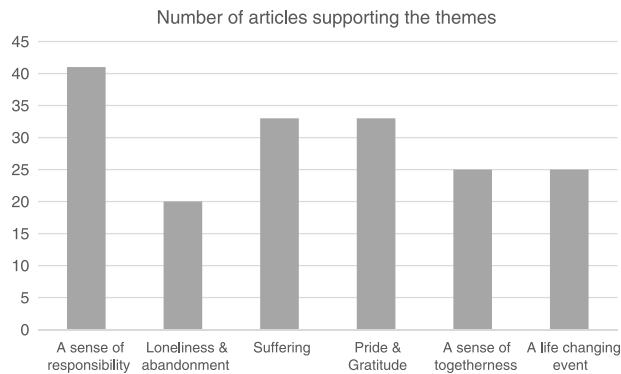


FIGURE 2. Number of articles supporting the themes.

the specified donor to act to relieve her/his suffering and/or risk of death.^{30,34,35,37-39,41,42,44,46,47,52,57-63,65} For the unspecified donor, the responsibility lies in the opportunity to help a needy fellow human being.^{54-56,67-70}

There are several motives behind the decision to donate. Once the donor makes the decision it is experienced as having reached a point of no return and the donor sees her/himself as the only option for the recipient.^{14,30-32,34-70} Both specified and unspecified donors usually have more than one motive for donation. The fact that the motives for donation often depend on the donor's relationship with the recipient as opposed to what is donated is well illustrated in the various studies.^{30,34,35,39,40,42,49,50,53,54,56,58,61,65,68,69} A strong desire to help and save or extend someone's life is the main motive for the majority of donors.^{30,34,35,37,39,40,42,53,54,56,58,61,68,69}

When the donation is specified the motive often includes a sense of moral obligation, while an unspecified donation is more likely to involve a feeling of personal satisfaction. Sometimes, the decision is driven by religious or spiritual beliefs.^{30,35,50,54,63,68,69} It was frequently stated by Christians that it is something you should do or that it is God's will that one should help others.

The strongest incentive for specified donors lies in parenthood. Parents will do anything for their child and constantly focus on their seriously ill offspring, even when she/he is an adult.^{34,40,52,57-60,66} Being a sibling implies an obligation to act in a loyal and responsible manner,^{37,40-42} which can also lead to ambivalent feelings about donation.^{34,40,42,46,63-65} Donating to a spouse or partner often includes a personal benefit, that is, donation improves the quality of life together.^{35,44} In addition to the wish to help, unspecified donation is driven by the desire for increased self-esteem by helping the less fortunate or being a role model, thereby creating the impression of being a better person.^{53-56,68-70}

Loneliness and Abandonment

Loneliness and a feeling of being abandoned are experienced by both specified and unspecified donors. The decision to become a donor is often made alone.^{34,35,42,46,47,53,58,68} Donors experience a sense of loneliness during donor assessment, first, because they are uncertain about being accepted as a donor and secondly due to the waiting period between the decision to donate and the actual donation.^{39,65} Throughout the donation process donors worry about various things. These worries are usually not discussed with anyone and contribute to the sense of loneliness, often because the donors sense that their worries are minor compared to the recipient's severe suffering.^{30,32,35,37,40,44-46,51,56,59,65,68,70} Donors are

not always acknowledged by their family during the donation process. Conflicts between their birth family and the family into which they married often occur in connection with donation, which increases their sense of loneliness.^{34,35,40,42,46,47,53,68} Their sense of loneliness grows due to feeling ashamed about being selfish by focusing on themselves and the burden of being a healthy donor while the recipient is struggling with a very serious disease.^{49,53,64,67} Donors express that they are ignored, neglected and suffer from lack of information.^{31,35,36,38-40,44,55,56,58,62,64-66,68} A common experience after the donation is the feeling of not being acknowledged and being both physically and mentally abandoned by healthcare professionals. Donors are left with a sense of being used and are disappointed about not being acknowledged. The lack of acknowledgement and follow-up postdonation results in feelings of uncertainty and abandonment.^{31,32,34,35,38-40,44,45,47,53,55,56,58,60,62,64-66}

Suffering

Suffering involves experiences of physical, psychological, and social difficulties. The donor evaluation can be painful and unpleasant,^{42,59} whereas the donation itself may cause pain, nausea, and tiredness.^{31,32,36,37,39,40,48,51,58,63,65,68} Some specified donors are afraid to donate and frightened of dying.^{32,34,36,40,58,63,64} Being ill when one was previously fit and healthy is sometimes experienced as a shock.^{31,37,53,58,64,65} Psychological problems such as anxiety, sadness, and depression may occur for both specified and unspecified donors.^{36-39,42,44,45,51,55,62,70} The uncertainty about the impact on their health and potential long-term complications causes worries and anxiety.^{32,34,56,58,59,63,64,68} Donors also grieve and feel guilty when the donation fails.^{32,38,44,62,64,65,67,70} An unsuccessful transplantation can be experienced as a shock, which might cause a donor to fall apart both mentally and physically.^{38,39,44,70} Being a specified living donor involves several roles simultaneously, such as being healthy and becoming a patient, being a relative of the recipient and a family member, all of which may contribute to social suffering.³⁷⁻⁴⁰ Social suffering also includes donors worrying about how their financial situation will be affected.^{31,35,39,45,46,65}

Pride and Gratitude

The donation gives the donor a sense of accomplishment and a feeling of pride about the act. The gesture of giving per se is associated with a sense of self-fulfillment.^{34,35,37,38,42,43,47,49,50,53,57,62,68} Specified donors get satisfaction from witnessing an improvement in the recipient's health and are delighted with how the transplant improves the quality of life for the recipient and her/his family.^{37,43,47,49,51,57} The pride in having donated often results in increased self-esteem as well as self-confidence and a feeling of being a better person, which applies to both specified and unspecified donors.^{14,32,34,37,49-51,54,68,69} After donation, the donor feels that nothing is impossible and she/he would do it again.^{50,51,53} Unspecified donors realize the importance of the donation when they receive a card from the recipient.⁵³

Donors view the donation experience as positive and rewarding, and are grateful to have been given the opportunity to save a life.^{30,32,34,35,37,38,55,59,63,68,70} They value their own health and appreciate that they have been able to help

TABLE 2.**The meaning of being a living donor: themes and quotations****A sense of responsibility**

- "The decision for me to do it was really very easy. There was really no choice. I think a person often feels- if only I had the power to save someone's life- and you wish for that power. This opportunity to be a donor kind of fulfills that wish." (study 34, page 177, kidney specified)
- "How could I ever regret donating was how I thought about it.if I don't do this, how would I live with myself if we don't at least try." (study 57 page 189, liver specified)
- "For me to have been able to donate my kidney to my husband meant a lot of things... I can say that because of me doing something he's healthy, and that makes me feel good. That makes me know that, okay, our family can continue on." (study 36, page 505, kidney specified)
- "I didn't even think about it. It was not even a decision I had to make. She was sick and I wanted to make her better...." (study 39, page 59, kidney specified)
- "My mother spent an hour on the phone trying to convince me not to do it, because she felt that I was being selfish towards my sons...that I really should be not putting myself in that position, so that was quite a shock, because that phone call came out of nowhere, but I stuck to my guns." (study 53, page 400, kidney unspecified)
- "At first, I was very nervous. I had never been hospitalized. I was very lonely. It was even difficult to get to sleep." (study 63, page 916, HSC specified)
- "The blood results were done, and I never heard a word and I was thinking why aren't I hearing back from them, why aren't I hearing that I've passed that part?" (study 55, page 117, kidney specified)
- "Sometimes I feel like I've been used and just kind of thrown away, because nobody ever really asks about me." (study 31, page 746, liver specified)
- "Maybe a phone call from a doctor or a nurse 1 or 2 weeks later and 4 weeks later. After all, the automobile service representative calls me to check to see if I'm happy with their work." (study 62, page 696, HSC specified)
- "I hoped for something from the hospital, they wanted me to be on the other side of the country in a couple of days and then it was like 'thank you very much'. I felt treated like a number." (study 65, page 1364, HSC specified)
- "It feels like having a gun put to your head, it's like being taken hostage, so what can you do, there is absolutely nothing... this is a decision about life and death, it's not about getting a pay rise or buying a car. This is real life drama." (study 58, page 374, liver specified)
- "I'm very scared. I'm afraid. I have to think that I have children, but what can I do? It has to be me! So it will be." (study 63, page 916, HSC specified)
- "The hardest part was being told that I was to be the donor. I fretted about it. There were nights when I couldn't sleep and I began to cry..." (study 32, page 59, HSC specified)
- "The lasting impression after the operation is pain, pain, pain." (study 58, page 375, liver specified)
- "The transplant coordinators beforehand are busy telling you how many people are walking around after a few days and bounce back. And you kind of have this impression that, not that it's easy, but that most people recover quickly. I don't know that that's true for everyone. I think the really difficult thing for me afterwards was actually the whole emotional impact that was kind of happening afterwards. So I think probably I got quite depressed, which again I found out later is common, but again no one told me that before." (study 55, page 118, kidney specified)

Continued next page

TABLE 2. (Continued)**Pride and gratitude**

"I feel very proud to have donated to my sister and the whole experience has been very positive for all of us. When I see her I feel really proud about what I've done, it's like an amazing experience. You feel you've done something really worthwhile in your life. I feel like it's maximum gains for my sister, her family and me because the way it's made me feel with relatively little cost." (study 43, page 1612, kidney specified)

"I read it and it was like basically this person says thank you because you've given me my life back. For me that card is so important and it's not one that I put away... it was like it bought home to me that this was a real person, it's not an abstract idea, a real person." (Study 53, page 401, kidney unspecified)

"It was the best thing that I have done in my life; I feel proud of myself." (study 42, page 1249, kidney specified)

"I think I look at myself as a better person... I guess when you stand in a room full of people and know you're the only one who gone through this, it makes you feel better that you have done something they haven't." (study 69, page 294, HSC unspecified)

"It's just like a brotherhood... I know somebody is suffering. And if I could match with someone, I could help. I am quite willing to give to anyone... I thought, 'Okay, it is for a brother or for a sister'. That's it. I did it."

(study 53, page 398, kidney unspecified)

"When you go through this process, you feel like you really belong with that person." (study 62, page 697, HSC specified)

"I still feel a very great closeness to her, and it's quite an interesting thing." (study 30, page 97, kidney specified)

"They said that it was an American woman who was even close to my age. ... This was interesting for me. I thought about what she would look like, and what kind of person she would be? Perhaps we had similarities?"

(study 70, page 7, HSC unspecified)

"Whenever anything goes wrong with him, such as having flu. I feel guilty, I think perhaps I have given him something he shouldn't have. "He and I, we are just like a single person." (study 32, page 60–61, HSC specified)

"Just to see my father happy, not grouchy... getting back to a normal life was just huge to see and... it warms me greatly to see that." (study 51, page 425, kidney specified)

"...The best thing that you could ever think of... probably the best feeling I've ever had in my life... when you actually donate to someone, it is a fantastic experience... you just come out of hospital pumped up, really. I mean, you just feel so great... You sort of come out thinking, 'Well I can do anything. Bring it on!' You're sort of Superman... it is probably the biggest thing... mentally and physically that I've ever done and probably ever will do. There's no doubt about that in my mind. I can't see anything

surpassing it really..." (study 51, pages 424–425, kidney specified)

"The donation opened my eyes to a whole different life. It just broadened what life is about. I think if something like this didn't happen, I would never know what people go through. To me, it makes me a little bit more compassionate towards other people who go through things like this." (study 60, page 55, liver specified)

"It made me realize who I am and what I want to be, the value of life. That you take things for granted or you can just let life pass you by and not do anything." (study 57, page 189, liver specified)

"Now I am able to understand the feelings a woman must have when she bears a child. Childbirth must be a very painful event but when the child is born, everything is forgotten. Perhaps it is a poor comparison because childbirth is much more miraculous, but I had similar feelings." (study 70, page 7, HSC unspecified)

A life changing event

someone less fortunate.^{37,38,49,55,65,68} Some feel privileged to be the chosen one and have the chance to save someone,⁶³ which they experience as an honor.³⁰ Being acknowledged by a phone call from the hospital gave donors an impression of gratitude and appreciation.⁴⁸

A Sense of Togetherness

For the donors a sense of togetherness with the recipient emerges, irrespective of whether the donation is specified or unspecified.^{40,67,70} Donors develop a special tie with the recipient, which can be life-long.^{30,32,34,37,38,42,65,70} Specified donation is important for the existence of the family and may unite it.^{35-37,40,42-44,46,47,59,60} Sometimes donation is a family decision, something one does together.^{37,40,46} The sense of giving life back to a loved one or significant other makes the specified donor and recipient feel closer.^{30,32,34,36-38,42,46,47,61-63,65} Family bonds can be strengthened as a result of donation and transplantation,^{37,38,46,47,60} as health is restored in the family.^{35,37} For the unspecified donor, the bond is created by sharing one's health with a person suffering from a serious illness. Sometimes an imaginary relationship is created that results in a perceived bond with the unknown recipient.^{53,70} Being acknowledged, for example, by an anonymous card from the recipient, makes her/him real.⁵³ However, some unspecified donors wish to remain anonymous and do not want to know about the recipient's outcome.⁶⁷

The well-being experienced by the donor is closely connected to the recipient's outcome.^{32,38,40,44,47,51,59,62,65,67,70} When the outcome is poor the donor becomes worried and emotionally concerned. As a result of the sense of togetherness, the donor feels responsible for the recipient's health after transplantation and wants to shield her/him.^{30,32,35,40,51,59,62,65,70} In cases where the donation fails and results in rejection of the organ or stem cells, donors experience a sense of loss of control. They might question the quality of the donated organ or stem cells and whether transplantation was the best option for the recipient.^{30,31,34,39,44,62,63,70}

A Life Changing Event

Living donation is a special life event for specified as well as for unspecified donors, with an impact on the donor's life and a clear before and after.^{14,30,34,37,38,42,49,51,53,57,60,68,69} The opportunity for the donor to make a difference and to give life to save another person who is suffering from a life-threatening disease is a great existential experience.^{32,37,38,40,46,47,49,60-65,68-70} The donation makes the donor revalue life and view it in a different way. Life has greater meaning, leading to a profound appreciation of life.^{14,32,34,42,47,49,51,54,57,59-61,64,66,70} For specified donors, it can be expressed as the rebirth of a loved one.⁴⁷ Unspecified donors' reward is a gift exchange, giving and receiving a gift—reciprocity.^{69,70} Some donors compared the donation experience to the greatness of giving birth, reflecting the giving of life in different ways.^{32,49,70}

DISCUSSION

To the best of our knowledge, this is the first synthesis of qualitative studies to include living kidney, liver, and stem cell donors. The fact that similar experiences were found among all donors is of great value both clinically and for future research.

Comprehensive Whole

The comprehensive whole and synthesis is that the essential meaning of being a living donor is that *one does what one feels one has to do*, involving 6 themes associated with living donation that are important for healthcare professionals to understand. When the studies were analyzed, differences in experiences due to what had been donated could not be found and the crucial issue is that one donates a part of one's body to save another person from a life-threatening disease. It is 'that' one donates and not 'what' one donates that is of importance for the meaning of being a living donor. Furthermore, the meaning of donation depends on the relationship to the recipient and it is the donation per se that has an impact on the donor and her/his life. The specific motives for donation are dependent on the relationship between the donor and the recipient. Regardless of type of graft or relationship, the overarching driver is a sense of duty to do what one feels one has to do.

Methodological Considerations

This synthesis covers all qualitative studies identified by an extensive electronic search process and manual searches. However, studies might have been missed due to different indexing in the databases. Our aim was to synthesize the knowledge of donors' experiences to understand the meaning of being a living donor, and therefore, qualitative studies performed before donation were excluded. A challenge faced by the authors was that the aims of the studies often focused on donors' experiences of problems or complications in conjunction with donation, as opposed to what was rewarding. However, the studies also included descriptions of the positive experience of being a living donor, which have been highlighted in our synthesis. One could argue that studies based on the same sample should be considered one study. However, we decided to include some studies with the same sample in our synthesis, as due to their different aims the results differ.^{30,39,40,42,55,56} It soon became obvious that the earliest studies performed in the late 1960s revealed similar donor experiences as newly published work. We therefore decided not to set a time limit for inclusion in the literature search. Study limitations are the exclusion of non-English language articles, and that 37 of the 41 studies were conducted in western countries. The experiences of minor, mainly stem cell, donors are not included in this meta-ethnography, as we chose to focus on the adult donor perspective. Our research team comprised experienced researchers and 2 clinical living donor coordinators, who are familiar with different types of live donation and qualitative research. Five of the authors have no experience of the field of living donation, which ensured that the other team members' extensive preunderstanding was constantly discussed and reflected on throughout the whole research process.⁷¹

Discussion of the Findings

Two excellent recently published syntheses have focused on the specific organ or stem cell donors separately and one of them also includes pediatric donors.^{72,73} The experiences from these syntheses are largely the same as our findings, although the themes differ due to the merging of studies of different donors' experiences. Our findings emphasize that the experiences are generic. Our synthesis focused on the donors'

experiences and interpretations of the process of being a living donor. In summary, the findings of this meta-ethnography are:

- One does what one feels one has to do
- The main issue is that one donates irrespective of what one donates
- For both specified and unspecified donors the relationship to the recipient determines the motives for donation
- The sense of togetherness with the recipient creates personal meaning.

The unspecified donor has made an active decision to step forward and offer to become a donor. Although this is often the case with a specified donor as well, an additional psychosocial strain is always involved. The situation for the specified donor might be emotionally more complex, for example, due to simultaneous roles; being a patient, a close relative to the recipient, and/or a family member, all at the same time as well as the fact that the actual relationship with the recipient may cause the donor undue coercion within the family. However, the situation of an unspecified donor might also be complex for various reasons, for example, negative family reactions to the decision to become a donor. When conducting the predonation evaluation, it is essential to be aware that each donor has several motives for donation. The prekidney donation studies performed by Lennerling et al^{74,75} guided the understanding of the motives for living donation, of which the 3 most common were: the wish to help, self-benefit, and identification with the recipient. Other motives included a sense of moral duty, external pressure, and increased self-esteem. Studies on kidney and stem cells donors report several motives for donation. The driving force behind all motives was the perception that donation was the only option, something one feels that one has to do,⁷⁴⁻⁷⁶ which is supported by our synthesis.

This synthesis revealed that the meaning of being a living donor is generic and not based on what one donates, but that one donates something from one's own body. The medical discrepancies regarding procedures and risks between kidney, liver, and stem cell donors are obvious, but the subjective experiences of being a living donor are very similar. The meaning of being a living donor comprises both positive and negative experiences that are elucidated in our 6 themes. A central part of being a living donor seems to be that the experience is multifaceted for each individual, involving positive and negative aspects of donation. Our synthesis revealed that differences in experiences are not connected to what has been donated but to whether the donor is specified or unspecified.

The donor's relationship with the recipient has a major impact on the motives for donation. Parents have the strongest incentive to donate, as they are willing to do anything for their child. If the child were to die because one lacked parental motivation for action the guilt would be unbearable and impossible to live with.^{52,58,66} The sibling relationship probably gives rise to the strongest moral pressure on the donor, both from her/himself and from close family members.⁷⁴⁻⁷⁹ In the case of partners or spouses, a strong incentive for donation is the wish for a better quality of life, the self-benefit motive.^{75,78} Because there is no actual relationship between unspecified donors and the recipient, their motive, apart from the wish to help the less fortunate, is often to increase their self-esteem.

Living donors experience a sense of togetherness with the recipient after donation, which creates personal meaning. The relationship often becomes closer. The donor wants to protect the recipient and feels responsible for her/his health. On the anniversary of the donation and transplantation, the donor can be acknowledged with a phone call or card, and it can also be celebrated yearly by the family, which strengthens the sense of togetherness. Even unspecified donation involves aspects of relationship as an imaginary bond is sometimes created between the donor and the unknown recipient. However, some donors prefer to leave the donation behind and go on with their life.⁷⁹

An important aspect for a donor is being able to help someone in need, which some donors experience as an honor. To have performed the donation, both passing the predonation evaluation and having donated for the purpose of saving or extending someone's life, makes the donor feel proud and grateful. Improved quality of life for the recipient after transplantation is rewarding and makes the donor feel good. The pride and gratitude associated with being a donor results in increased self-esteem. In a Norwegian study, it was shown that kidney donors experience a better quality of life after donation.⁸⁰ Some unspecified donors do not distinguish between helping a significant other or a complete stranger. They wish to donate at a time point when they are able to do so, and avoid thinking about what might happen if a loved one were to become seriously ill. They want a fellow human being to lead a normal life with increased quality. The donation serves as an unconditional gift to a fellow human being.^{54,81} Zeiler⁸² refers to empirical studies of persons who have acted as saviors of complete strangers in various situations. When they looked back they described their actions as something completely natural, the only possible option and something they just did. They viewed themselves as part of a human entity. This finding is of value as donation from an unspecified donor might be less complicated than donation to a significant other.

Being a living donor is a life changing event. Because the donation means saving or extending someone's life, it will affect most donors for the rest of their lives. Living donation implies reciprocity, because the donor gives something from her/his own body with the intention of gifting life or health to another human being. In return, the donor feels that her/his life has been given a greater meaning due to having had the opportunity to make a profound existential difference for another human being.

As early as 1968 Fellner and Marshall¹⁴ reported that living kidney donors felt used and abandoned by healthcare professionals after donation. It is remarkable that 50 years later, living donors still describe the same kind of experiences.^{79,83,84} Acknowledging the donor's effort is essential. A proper postdonation follow-up program for living donors aimed at reducing their sense of loneliness and abandonment is a prerequisite. Lack of follow-up might cause stress, uncertainty, and in the worst case, depression. Possibly stem cell donors are the most neglected donors due to the fact that stem cell donation does not involve major surgery and the hematopoietic stem cells are regenerative. However, our synthesis revealed the same experience of loneliness and abandonment among all living donors. Providing support to interpret symptoms and continuous information about the process and recovery will reduce the sense of loneliness

and abandonment, thus potentially diminishing the stress.⁸⁵ Donors also expressed a wish to share their experiences with other donors, because they are the only ones who can really understand the situation.³⁸ The importance of acknowledging donors postdonation has been greatly underestimated and is an aspect that needs to be improved. A European study by Lennerling et al⁸⁶ showed that only 60% of the transplantation centers included psychological screening of potential live kidney donors. Follow-up postdonation was conducted in 83% of the transplantation centers, of which 17% involved a psychosocial evaluation. The new guidelines for living kidney donors published in 2017 state that a personalized care plan should be provided and that follow-up, including a review of psychosocial health and well-being, should be performed at least annually.⁸⁷ We argue that this is applicable to all types of living donor and is one component of protecting them and ensuring the quality and safety of live donation.

CLINICAL IMPLICATIONS

The results of this meta-ethnography of living donors provide insight into their experiences and implications for their psychosocial care. We suggest the following for all living donors:

- Psychological screening before and after donation to be able to support the donor throughout the donation process.
- Provide a clear and reliable timeline of the evaluation process, as well as regular feedback on results and tests.
- Provide information based on the donor's perceptions and preferences.
- Before donation, all donors should be given the opportunity of meeting other donors who have already made their donation, to share experiences.
- The donor should be acknowledged for the donation by the healthcare professionals.
- Donor follow-up appointments or counselling should be mandatory after donation.
- Recipients of unspecified donors should be encouraged by the transplant team to send a "thank you card" anonymously.

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