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The lived experience of living liver donors : a phenomenological study

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THE LIVED EXPERIENCE OF LIVING LIVER DONORS: A
PHENOMENOLOGICAL STUDY

by

Sarah Ellis Ross Greenwood RN, BScN, CPMHNC

Ryerson University, Canada, 2011

A thesis

presented to Ryerson University

in partial fulfillment of the
requirements for the degree of

Master of Nursing

In the Program of

Nursing

Toronto, Ontario, Canada, 2011

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The Lived Experience of living Liver Donors: A Phenomenological Study

Master of Nursing, 2011

Sarah Ellis Ross Greenwood

Master of Nursing

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Abstract

Thousands of Ontarians die annually waiting for a deceased donor liver transplant. Merging realities of chronic donor shortage and success of living kidney donation stimulated interest in living liver lobe donation. Remaining unexplained are the persistently low rates of live liver donation despite media campaigns. The purpose of this qualitative study was, from a phenomenological approach, to explore and understand the meaning of the lived experience of living liver donors. Four participants in this study felt personal enhancement through donation while acknowledging present gaps in living donor awareness. Arising from this current study, two themes emerged. These themes are: (1) The embodied experience of being a living liver donor and (2) Ethical responsibility to one another and to the world. Recommendations included establishment of platforms and symposia for donors to speak about donation experiences. Living liver donors have much to offer in reimagining current donation awareness campaigns.

Acknowledgements

Committing to and writing this thesis has been a challenging, interesting and extremely stimulating experience. This work would not have been possible without the help and support of many people who contributed to the completion of this work. It is with real pleasure, mixed with communal relief, to be able to thank everyone who encouraged me through this journey.

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I am most grateful for the generosity and insights provided by the participants in this study. I hope I have fulfilled my commitment to them to complete the study and continue to explore ongoing experiences of living liver donors.

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models, professional mentors and embody my notion of truly committed nurses. They have offered support, friendship and a few swift kicks to keep going throughout this thesis. Thanks are not enough.

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This past summer, my niece and namesake came to Toronto to explore research and a fledgling interest in healthcare. Written in a personal note at the end of the summer, she said her experience awakened her to the importance of family. I am grateful to my whole family for their support and forbearance as I moved through this work. I wish to express deep gratitude and love to my mother Nancy Chapman Greenwood for her insatiable curiosity - a born phenomenologist. Profound thanks to my father Dr. Frederick Greenwood for his insights, care and interest in his patients' experiences. I also want to thank my brother Dr. Hamilton Greenwood, a wonderfully skilled teacher and listener, always bringing out the best in people. Hamilton has been one of my principal supports throughout this thesis and I am most grateful for his guidance.

Dedication

Hestia

First,

seek

a settled home

for your bees,

a place, a hearth,

something not violent,

yet resembling a roaring fire,

-safe-

“whither the winds

may find

no access”

I dedicate this thesis to my husband Simon Pettet who provided hearth, heart and ear for this study, and always.

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CHAPTER 1: INTRODUCTION

One of the major advances in modern medical technology is organ transplantation; however, a chief concern has been the ability to provide this life-saving procedure to many patients in need. A global shortage of organ donors is a reason the growing demand for human organ transplantation remains unfulfilled. Potential recipients may wait for years before a suitable organ can be found. Underscoring the urgency of this problem is the length of wait times between listing and organ donation, increasing the potential for medical complications and/or death (Shanteau, Jackson- Harris & VandenBos, 1992). Despite campaigns to promote transplantation, a high refusal rate persists. Influencing factors include widespread misunderstanding of religious principles, fear, prejudice, and complex social, moral, and cultural attitudes in the medical community and in society (Fetrin, Pegoraro, Rago, Benciolini, & Pasquato, et al. (2008).

Alluding to most generally agreed upon studies, an important factor for consenting or declining organ donation is discussion and knowledge of the deceased person's wishes before death occurs (Sque, Long, Payne & Allardyce, 2007). Differences can arise when the predetermined wishes of the deceased donor conflict with those of the relatives. Despite the patient's acknowledged desire to donate, these decisions ultimately rest with the family, and are dependent on several factors (Sque et al., 2007). Adding to the increasing shortage of deceased organ donation is tension stimulated between opposing wishes of the transplant team, Intensive Care Unit staff, and particularly with the family of the deceased (Morgan et al., 2008; Shanteau et al., 1992; Sque et al, 2007; Surman et al., 2005). Semantic confusion about language used for

organ donation perpetuates ongoing strain. Using transplant policy metaphors of the *gift of life* does not palliate and mask grief.

Evolving over the past 50 years from an experimental surgery to the treatment of choice, liver transplantation is viable for thousands of people who suffer from end-stage liver disease. Unfortunately, a supply of suitable deceased donor livers for transplantation has not met exponentially increasing demand (Reichman et al., 2010). Enhancing success with transplantation are advances in immuno-suppression, and prevention and treatment of infection. Improving technology also has influenced the increased number of patients considered yearly in evaluation for transplant; (Svaneus, 2009) nevertheless, cadaveric donation rates have remained relatively unchanged from 1994-2004 (Trillium, 2005).

Liver lobes have unique abilities to regenerate within 6 to 8 weeks, making living liver lobe donation possible. Success with living kidney donation, together with a chronic shortage of available cadaveric organs, has stimulated research and interest in development of living liver lobe donation. Beginning with the first adult to paediatric donation in 1989, thousands of recipients have undergone this surgical procedure with results comparable or better than deceased donation (Trillium, 2005).

Purpose of the Current Study

The purpose of this qualitative study was, from a phenomenological approach, to explore the lived experiences of living liver donors. Sharing the unique experience of being living liver lobe donors, this group was able to describe expressed or tacit considerations around the experience of stepping forward for organ donation. Four living liver donors took part in this phenomenological study, through the use of open-ended questions in semi-structured interviews.

Significance of the Problem

The Multi-Organ Transplant Centre is a priority program within a large Canadian, urban, quaternary hospital. With an approximate 13% mortality rate in 2010 after being listed, patients can expect to wait as long as three years for a cadaveric liver transplant. There are many causes of liver failure and while transplant is the ultimate treatment it is not a cure. Since 1996, more than 400 living liver lobe surgeries have been performed; however, of the 400 cases, over 50 %, or 200 patients have donated a liver lobe in the last three years (R. Smith, personal communication, October 20, 2010). These statistics highlight three unique but interconnected problems; a lack of cadaveric donors, increased demand for living donors, and a geometric explosion calling for expansion of the living liver donor program (R. Smith, personal communication, October 20, 2010).

This largest living donor program in Canada has generated multiple quantitative studies about surgical aspects of living liver donation procedures, as reviewed in Chapter 2. Numerous quantitative quality of life studies justified and promoted living donation as a viable option for end-stage liver failure. The uniqueness of this current study was the phenomenological nature of inquiry through exploring qualitatively, participants' experiences of being live donors. Little is known or described in the literature about the experiences of living liver donors. To date, there are no published phenomenological studies of the lived experiences of living liver donors found in the literature. Inclusion of the experiences of living *kidney* donors provides comparative data found in the literature review.

Background of the Problem

Of nearly 240 listed, potential liver transplant recipients waiting in 2010, 208 recipients received liver transplants. Remaining unaccounted were patients too ill to be listed. Also

unreported are a third of previously listed patients who died waiting for a liver transplant. In 2010, only 42 people were living liver donors in Ontario (Trillium 2011). Waiting in 2001, were 264 listed potential liver recipients with 34 living liver donation, rates comparable to those in 2010. These numbers suggest donor rates and actual transplants performed during that decade remained virtually unchanged (Trillium 2011). Statistics illustrate the divergence between increased need versus actual donation.

Living liver donation provides several advantages over cadaveric organ donation. Shortened waiting times directly impact medical complications and risk of death for the recipient. Living donors tend to be younger and having withstood challenging medical work-ups, living liver lobe donors are in better health and are therefore able to provide better organs than deceased donors (Trillium 2005). Finally, reducing organ retrieval and implantation lag time through scheduled surgery critically and positively affects integrity of the transplant (Trillium Gift of Life, 2005).

Statement of the problem. Thousands of Ontarians die annually waiting for a cadaveric liver transplant. Statistics for Ontario in 2010 reported 228 people are, to date, waiting for a liver transplant. Of all liver transplant recipients, 143 have already obtained a deceased donor organ, while only 43 received a lobe from a live donor this year (Trillium, 2010). Living liver donors need to speak about their experiences as donors. Describing shifting paradigms and semantics solely from the gift of life to include living donor experiences of embodiment and interconnection with others will enhance knowledge around offering or refusing live liver donation. Articulating what they are living through will increase knowledge and understanding of what it means to be a live donor. Exploring and describing experiences may positively affect live liver donation rates, and could influence future policy changes.

Summary

The purpose of this qualitative study was, from a phenomenological approach, to explore the lived experiences of living liver donors from a hermeneutic perspective. Describing the purpose statement, background, and significance of this problem demonstrated the need for further investigation in this area. While an abundance of quantitative literature measuring aspects of living liver donation exists, a gap in knowledge of participants' lived experiences remains unaddressed. Choosing to interpret this study from a hermeneutic phenomenological perspective, incorporating van Manen's human science, a pedagogical, methodological approach added richness to experiential descriptions of the lived experience of living liver donors.

This current study is important in gaining understanding derived from donor perspectives. Receiving new knowledge through interactive dialogue and participant-led discussions uncovered values and concerns held by participants in this study. As well, participants stated there were emotionally positive benefits from sharing experiences related to living donation. The study could influence both living donation rates and living liver donor policy if patient perspectives and experiences are recognized and adopted. Following in Chapter 2 is a synthesis of existing living kidney and liver donor literature. Appraising and reflecting on current literature of living donation, the focus of Chapter 2 is to explore research addressing embodiment, ethics, and quality of life, themes most prevalently found in the current literature.

CHAPTER 2: REVIEW OF THE LITERATURE

There is a growing body of literature about living liver lobe donation that will be discussed in this chapter from the following perspectives; embodiment, ethics, quality of life, psychological risk factors in donor selection, and reviews of post surgical interventions. The majority of data were quantitative and often framed in the context of improving quality of life for the recipient, while frequently passing reference to added benefits for the donor. Reviewed under the following headings were six themes emerging from a comprehensive literature search of quantitative and qualitative studies about living donation. Interestingly, these areas of interest reflected evolving thematic facets, later described and interpreted in Chapter four, and included embodiment, ethics, quality of life, donor selection and experiences of living donors. The complexity of the donor experience, what is valuable and important to the donor, and what the experience of donating a liver lobe is like; has not, to date, been well described in the literature.

Title Searches, Articles, Research Documents, Poetry Books, and Journals

Accessing and exploring databases such as CINAHL, Medline, Pubmed, ProQuest, Elsevier, and Google Scholar generated the results for this literature review. This search combined key words and phrases: living liver donor/transplant and meaning, motivation, phenomenology, Heidegger, van Manen, lived experience, embodiment, quality of life, ethical issues, qualitative research, psychological screening, impact and outcomes, spirituality, and life changes. Searching for similar key words and combinations for living kidney donation experiences yielded additional qualitative data.

The lack of qualitative data about experiences of living liver lobe donors provided the rationale for the inclusion of living kidney donor literature. Living kidney transplantation procedure is more than 50 years old, and has therefore generated a larger body of research. Some

The Lived Experiences

studies reviewed were several decades old, but reflected both historical and seminal importance in organ donation literature. Comparing and supplementing the paucity of qualitative results related to living liver donor studies to renal transplant literature provided additional insights. Results from the literature search included academic books, peer reviewed journal articles, scholarly journals, magazine articles, poetry, literary criticism books, and Internet poetry sites.

Literature Review

Embodiment

Who owns the body and what responsibilities are conferred on the owner were central themes when considering the relationship between embodiment and the lived experience of living liver donors. Understanding the significance of the act in offering organ donation initiated reflection about embodied interrelations *within* the self and with others. The language of commodification was too simple to capture everyday intuitions about organ donation (Schweda et al., 2009). Lacking depth in capturing what is at stake in everyday life situations regarding organ donation, commodification, reduced to its essence, is taking something that is not for sale and turning it into a service or an article of trade. Schweda and Schicktanz (2009) identified commodification discourse touching on strong intuitions about the nature of the body and moral implications of ownership and use. Participants in this study found intuitions were not easy to explain or translate into rational, inter-subjectively convincing bioethical arguments (Schweda & Schicktanz, 2009). In contrast to one single paradigm, Schweda and Schicktanz observed plurality of different body conceptions in their qualitative, empirical study regarding organ donation (2009).

Metaphors included ‘harvesting’ the organs, alluding to agricultural and organic images for organ donation, and implied a natural, life-sustaining act. The ‘spare parts’ paradigm

employing metaphors of being car-like, supported a mechanistic functionality of the body. As an example of mechanistic belief, one participant in Schweda's 2009 study insisted "I have got 'Mercedes' lungs... I want 'Mercedes' lungs or I die...I mean it... I don't want 'Lada'" (Schweda & Schicktanz, 2009, p. 5). Representing just two examples of separate but dominant themes of self-perception and bodily rights illustrates the recurring complexity of describing participants' confounding attitudes towards donation (Schweda et al., 2009).

Few researchers have explicitly connected organ transplant experiences and cultural views to the notion of embodiment. One sociological study interviewed 19 families who consented to donate a relative's organs. Perceptions of embodiment- whether one has a body or is a body- varied among this sample and in some cases, embodied awareness affected decisions to donate (Haddow, 2005). Including discussions of 'who one is' also established importance to investigate 'who one was' to family members. Impacting on the lives of the bereaved, meaning around what happened to self-identity at death and the bonds formed as embodied beings, led to a more complex and subtle portrayal of the different understandings of embodiment (Haddow, 2005). Haddow (2005) asserted that respecting the deceased's body is not just about dying and death, but includes experiences of living, the identity of the deceased, and the strength of social relationships.

Anthropologists have investigated broader cultural attitudes toward the body and the meaning of transplantation. Joralemon (1995) framed popular discourse about organ transplantation in terms of two familiar, but opposing American values, altruism and individual rights. He argued as much as drugs suppressed the body's instinct to attack foreign tissue, widespread intuitions about inseparability of body and personal identity persisted. Attaining

social approval for organ transplantation required dampening of one's own sense of corporeal identity to include concepts of donating and receiving organs (Joralemon, 1995).

Ways of conceptualizing the act of donation has led to misunderstanding for donors and recipients. Negotiating semantic confusion created disparity between paradigms of spare parts and agricultural metaphors, personal altruism and obligation. Dominant medical rhetoric regarded the procedure as an exchange of spare parts, encouraging recipients to dissociate from their donors (Haddow, 2005; Joralemon, 1995). This approach encouraged a mechanistic paradigm to veer from speculation about the dead donor. Recently, some critics have begun to unpack previously unexplored meaning behind unanticipated donor and recipient distress. Thoughtfully entering into discussion about corporeal generosity generated by the donor's gift of life has initiated a process of examining the lived experiences of both donor and recipient (Diprose, 2002; Hird, 2007).

Even when surgically successful, transplant recipients have felt isolated through struggles with altered perceptions of self. Recently, Rivest, Leclair, Achille, and Ummel designed and implemented a qualitative pilot study to explore the feasibility of body mapping workshops with five liver transplant recipients (2010). Body mapping, an artistic expression of a person's self-perception and understanding, is a creative tool for participants to experience their own body shapes and sizes (King, 2004). Painting self-portraits incorporating transplanted organs and including verbal descriptions created a powerful means of self-expression. Generalizing benefits for other transplant donors and recipients, this pilot study offered possibilities for exploration of embodiment in living liver donors.

In a densely written philosophical reflection about corporeal ethics, Fielding cautioned against considering human beings as storehouses of material used for biotechnological systems

in the future (1998). The author spoke to Heidegger's concepts of essence and systemicity, referring to commodification of the body. Warning against technological simplification of a multifaceted issue, consideration of humans as storehouses for spare parts would significantly denature the complexity of everyday life (Fielding, 1998). While not able to speak, the pre-articulate body had its own way of knowing itself, attending to and understanding embodied experiences. In bioethical discourse, ignoring the experiential wisdom of being embodied agencies concealed danger in perpetuating acceptance of bodies as commodified systems, and harvesting spare parts for biological use (Fielding, H, 1998).

In summary opposing values of altruism and individual rights, embodied generosity and spare parts paradigms, furthered discussion around organ donation (Joralemon et al., 1995). In particular, concepts of commodification, of having a body versus being a body added complexity to issues of being embodied and having rights to one's own body. Lack of knowledge and burgeoning interest about distress for both donor and recipient highlighted the need for further exploration of embodiment in living liver donation. This investigation may generate interest beyond the currently held, predominantly mechanistic viewpoint of living organ donation surgery.

Ethics

The growing acceptance of living liver lobe donations has partially alleviated gaps between increasing demand for transplantable organs and ability to meet these needs. Bridging the gap within transplant surgeries with live donors could reduce an exponentially increasing organ shortfall each year. This surgical intervention attempts to address the dilemma of supply and demand; however, putting healthy individuals through surgery imposes risks, and is not without ethical considerations (Crowley-Matoka, Siegler & Cronin, 2004).

Through increasing demand for living donor participation, Surman, Fukinishi, Allen and Hertl suggested this claim has also increased the burden of decision-making on donor candidates (2005). Challenging historically paternalistically held principles of *primum non nocere*, the medical assertion to first do no harm, sparked interest in ethical principles of personal choice and surgical practice through pressure from living liver donors (Surman et al., 2005). Fully informed, voluntary use of donor candidates gained public acceptance so long as the donor's decision was not associated with psychological or financial coercion.

Shifting the responsibility of decision-making from the surgical team to potential donors reflected current zeitgeist in medical ethics, placing greater value on patient autonomy (Surman et al., 2005). Conflicting ethical issues included the strategic message and attribution of meaning; dialogue with the surgeon of possible adverse events and experience of discourse by the surgical candidate. Perceiving information as reassuring simply because the surgeon must be honest and therefore capable offered patients a sense of freedom from danger (Felner & Marshall, 1968). The ethical dilemma here was the potential lack of clarity in understanding surgical risks perceived by donor candidates. Incomplete understanding or misinterpretation of surgical risk raised ethical concerns over whether objective informed consent truly exists (Felner et al., 1968).

Lacking evidence-based data to objectively sort through inherent differences of meeting the competing needs of donor and recipient, Surman et al. explored ethical conflict by turning to kidney donor literature (2005). A highly motivated donor who stood to benefit from the surgery made ethical tensions less ambiguous. Lennerling et al. (2008) reasoned there are positive aspects and improved quality of life for spousal kidney donors, reporting these donors were

highly motivated and stood to benefit from the surgery. Living liver donors could benefit from this cautiously extended premise as well (Surman et al., 2005).

Reporting experiences of spiritual or intellectual fulfillment, some donors recounted improved senses of self worth. These findings raised issues of guarded and unsupported evidence about the meaning of altruism and donor-derived benefits. Ultimately, Surman et al. supported an ethical option, encouraging colleagues to view the donor as a surgical patient for whom the operation is merely that- a procedure with the usual attendant risks and benefits (2005). This reliance on medical paternalism opposed the viewpoint of donor autonomy, and did not address the lived experience of embodiment in living liver donation.

Psychological benefits for living liver donors were intangible and difficult to establish. Reported advantages of subjective donor-derived benefits strengthened ethical justification for living anonymous donation (Wright, Ross, Abbey & Levy, 2007). Recounting psychological benefits included tangible expressions of altruism, motivation, and the act of donation consistent with spiritual beliefs. Further, exploring donor-derived benefits allowed expression of a sense of gratitude for the chance to donate and supported endorsement of ethical considerations for autonomous patient decisions (Wright et al., 2007).

Non-cognitive, visceral, irrational factors often drive health-related decisions (Morgan, Stephenson, Harrison, Afifi, & Long, 2008). Variables in this quantitative study included knowledge, attitude, social norms, and behavioural intentions. Revealing additional factors evolving from the study included exposure to information, and spiritual and cultural values. The authors expressed bewilderment with donor patients' decision- making processes, perceived as driven by non-cognitive, irrational factors. Countering these observations, Morgan et al. (2008)

insisted donor decisions though not based on linear, rational thought processes must be respected when promoting organ donation. Incorporating and understanding of both cognitive and non-cognitive factors could positively influence the outcome for increased organ donation (Morgan et al., 2008).

The majority of reviewed papers reported immediacy of donor candidate decision-making processes in response to donating a liver lobe. In contrast, Parisi and Katz's study of commitment to posthumous donation developed a more holistic approach to measuring attitudes toward donation (1986). Decisions about organ donation did not vary along a single continuum; people held both positive and negative attitudes simultaneously. Recognition of potential donors' abilities to embody simultaneity of both positive and negative attitudes towards donation underscored acknowledgment of complexity in decision-making processes (Parisi & Katz, 1986).

In the early years of living kidney donation, MacFarquar described a "skeptical and deeply suspicious view" of altruistic donors as a reaction of some transplant surgeons (2009, p. 43). Fox and Swazey spent more than 40 years observing transplant centres, and believed transplant surgeons and psychiatrists went to extreme lengths to uncover emotional conflicts and ambivalence living below the potential donor's decision to donate a kidney (1992). No single standardized method of donor assessment criteria existed between centres. Turning away potential living donors, if motivation was deemed inadequate, became the safe stance for many transplant programs (Fox & Swazey, 1992).

This issue was partially circumvented with adherence to rigorous psychosocial assessment of regimented emotional hygiene, and safeguards for potential donors (MacFarquar, 2009). Rationalizing the need for rigorous assessment as a precautionary measure became

acceptable practice. Health care members of the transplant programs acknowledged these precautions would no longer be needed once living donations became standard procedure. Arising ethical issues of obligation and gratitude intensified moral conflict when saying ‘thank you’ was deemed inadequate, and reciprocity was not possible (MacFarquar, 2009). Fox and Swazey (1992) remarked on anthropologist Marcel Mauss’ observation there was “something tyrannical about a gift” (p. 40). They further mentioned reflecting on bioethicist Leon Kass, who said “Why does the benefactor love the recipient more than the recipient loves the benefactor? Because the benefactor lives in the recipient, the way the poet lives in the poem” (Fox & Swazey, 1992, p. 44).

To summarize, considering the complexity of ethical issues generated by transplants, a surgical procedure that is just 20 years old and places healthy individuals under physical, psychological, and financial stress, with no known long-term outcomes is not without risk. The current trend in assessing donor candidates emphasizes the absence of psychopathology rather than discursive engagement about a desire to donate, and attends to concerns expressed by potential candidates. Medical paternalism did not absolve the transplant team from ethical responsibility. Evidence of suspicion for donor derived benefits and motives existed despite donors’ consistently expressed interest in helping another. A return of medical paternalism in the ethical assessment of potential candidates inherently rejected efforts to recognize potential living liver donors as autonomous beings.

Recognizing donor-derived benefits, so long as ethical considerations have been met, has promoted living donation in recent years. Consideration of this paper’s research question “What is the experience of being a donor?” and interview questions such as “What types of factors led

to the consideration of becoming a donor?” may further understanding of what it means to be a live donor by dispelling mutual donor and transplant team wariness. Meeting joint goals of increased living liver donation through thoughtful ethical consideration may truly begin with open discussion and engagement between donors and transplant team members.

Quality of Life

Researchers have long been interested in exploring aspects of quality of life for both live kidney, and more recently, living liver donors. There are many recurring limitations in selected quality of life studies for this literature review; the most prevalent issue being the predominantly quantitative nature of the studies. Qualitative studies were rare, using the databases and word search combinations previously described. Qualitative studies were hugely underrepresented in this literature review. Quantitative studies did not contribute any new knowledge in living donor literature for the purpose of understanding the lived experience of living liver donors in this current study.

Selecting predetermined domains of interest in measurable questionnaires, quantitative researchers imposed limitations on donors’ own definitions of quality of life. Measurement tools used to evaluate quality of life, distress, and satisfaction did not allow for exploration of thought and emotion around predetermined topics. Omitting possible topics of interest believed important for study participants underlined the limitations of quantitative research for this current study.

Demonstrating significantly increased overall recipient survival compared with deceased donor transplant recipients, adult living liver donor transplantation emerged as an alternative to deceased donor transplantation. Historically, sceptical criticism discouraged implementation of this surgical procedure in western countries and the United States, despite clear benefits of living liver donation for organ recipients (DuBay et al., 2009). In this largest single centre report to date

on quality of life in living liver donors, four determined categories of interest indicated pre-donation decisions: motivations to improve the recipient's health, motivation to be a good Samaritan, and concerns related to the donor and with self. Dominant interest in this study focused on positive benefits for recipients. Donor concerns were of adjunctive significance, principally due to positive long-term outcomes for recipients (DuBay et al., 2009).

Feltrin's quantitative study on donation and quality of life for living kidney donors also focused primarily on recipients. The author emphasized decisions arose from the desire to improve recipients' quality of life and relieve suffering. (2008). The study pointed to a desire for release of anxiety during the waiting period for a cadaveric donor (Feltrin et al., 2008). Feltrin's study considered donor quality of life, but only in relation to that of the recipient. A serendipitous finding previously unreported in the literature demonstrated improvement in the recipient's health, led to donor derived benefits. This encouraging finding was one of the cited reasons for offering to donate (Feltrin et al., 2008).

Considering living liver donors' quality of life and attitudes towards donation only recently shifted focus from recipient gains, to include the significance of and appreciation for, donor-derived benefits. Results of a retrospective, quantitative study on psychosocial aspects of adult to pediatric living liver donors, Kroencke, Wilms, Broering, Rogiers and Schulz (2006) examined effects of donation with 36 participants. Kroencke et al. briefly mentioned emotional burdens placed on donors in relation to the overall psychosocial impact on the entire family (2006). Seventy potential respondents were polled to elicit participation in the study, and only 51% of donors agreed to enrol. Results from this quantitative study were limited however by lack of generalization due to low response rates (Kroencke et al., 2006).

The Lived Experiences

Donor families experienced stress when two family members underwent living liver donor surgery simultaneously. Donors reported decisions to donate seemed less difficult than expected when considering the potential negative outcomes of refusing a liver lobe to a child. Placing the focus on issues of improved quality of life for the entire family, this quantitative study of parents donating to their children failed to fully address donor concerns, centering discussion on relationships between parent and child, (Kroencke et al., 2006).

Treating potentially life-altering surgery as another elective procedure was tempting in light of the medical acuity of patients. Requiring life-saving organs and meeting the reality of an insufficient supply of cadaveric donors sometimes led to surgical decisions inconsiderate of living donor needs. Meeting all ethical standards with extreme care at the point of donor evaluation ensured safety and respect for the parent donor (Kroencke et al., 2006). As a preferred research method, adopting a qualitative method of inquiry addresses a richer description of the potential loss of a child, alleviation of burden of care through transplant, and concerns for oneself.

Considering quality of life for the donor more extensively, Verbesey et al. concluded living liver donors perceived the act of donation to be an overall positive experience (2005). Suggestions to enhance donors' experiences in the future included an emphasis on donors being considered as separate patients from recipients. Improved quality of care highlighted the importance of excellent pain control for post surgical living liver donors. Outlining a plan for provision of follow-up in transplant clinics for donor specific medical and psychosocial issues supported opportunities for donors to meet others for discussion of donor-specific issues, stressing the time required to return to normalcy (Verbesey et al., 2005).

When generating research around quality of life for living liver donors, some studies suggested donations had mixed positive and negative impacts on donors' overall sense of wellness (Beavers et al., 2001; Bronner et al., 2002; Brown et al., 2008; Crowley- Matoka et al., 2004; DuBay et al., 2010; Erim et al., 2006, 2007; Fisher et al., 2005; Kroencke et al., 2006; Lennerling et al., 2003; Trotter et al., 2007). All cited authors reported an overwhelming majority of donors would donate again, despite rare instances of post-operative complications. Most authors focused studies on the donor primarily in relation to the state of health, illness and surgical outcomes for liver lobe recipients. Remarking on donor impact and experience were of secondary interest and concern.

In four living liver donor studies, DuBay et al. (2010), Erim et al. (2006, 2007), and Trotter et al. (2007) reported quantitative data citing very few cases of severe psychological and psychiatric stress on donors after living liver transplantation. In a multi-centre, quantitative study, Trotter et al. (2007) described the negative effects of being a living donor. Sixteen of the 392 donors evaluated for distress reported one or more moderate to severe psychiatric complications post donation. No discussion in the text included donors' expectations for life after donation or references to pre-morbid psychiatric diagnoses prior to liver lobe donation (Trotter et al., 2007). Speculating donors had unrealistic expectations for life after surgery, researchers in this study stated donors were unprepared for post-operative physical and emotional complications. Proactively advocating for rigorous psychiatric assessment and careful follow up could improve donor transplant outcomes (Trotter et al., 2007).

“Would you donate again?” (Erim et al., 2006) inquired, but did not segue with the more information yielding, meaningful question “why?” and “what factors would help you make this

decision?” Addressing issues of surgical complications and financial impact on recipients and donors in these single and multi-centre quantitative studies were limited by low response rates and failing to fully describe the impact of donation (Erim et al., 2006, 2007). Further, the authors stated six donors reported psychiatric complications, and speculated complications were related to unrealistic outcome expectations. There was limited discussion exploring expectations held by donors. Erim et al. advocated for emphasis on further research but did not address possible factors influencing the emotional impact on the decision to donate (2006, 2007).

Potential kidney donors often reported they stepped forward to donate so a proposed recipient may have a better life (Brown et al., 2008). Using a qualitative study informed by phenomenology, authors examined decision-making processes, experiences and factors influencing living kidney donation. Desire to help another was the dominant expressed reason for offering donation. Influencing factors included a sense of guilt, religious motives, and pressure from others. Supporting additional positive, contributing factors included benefits of an increased sense of self-esteem (Lennering, Forsberg, Meyer & Nyberg, 2003).

Reporting similar discussions of increased self-worth through the act of donation further supported reasons to explore embodied experiences of living donation with qualitative studies (Brown et al., 2008). Three key themes emerged from this study: 1) A desire to help, 2) faith, spirituality and the cycle of life and, 3) the life changing impact live kidney donation had on participants’ lives (Brown et al., 2008). Attention to lived experiences of the kidney donors and descriptions of these three dominant themes reinforced attention to relevant issues for donors, suggesting consideration of donors’ psychosocial needs, pre and post organ donation.

Further supporting the need for increased qualitative investigation was a long-term, quality of life exploration among adult to paediatric living liver donors (Crowley-Matoka, Siegler & Cronin, 2004). Reflecting on the traditionally focused importance of medical issues post transplant, Crowley-Matoka et al. (2004) emphasized quality of life concerns established by participants. Central and repeating themes included perception of being a non-patient, changes in family role and marital strains, perceptions of donation, and transplant being a finite state. One participant in this study reported “A lot of people assumed that you’re done with the transplant and now there’s nothing to worry about” (Crowley-Matoka et al., 2004, p. 747).

Other concerns revealed themes about financial worry and return to normalcy for donation and transplant. Fundamental to this study, Crowley-Matoka et al. (2004) recommended sustained follow-up for donors, recommending donors would appreciate added care. These observations serve to underscore issues of persistent dissatisfaction in long-term quality of life studies, asserting embodied experiences continue beyond medical consequences of donation (Crowley-Matoka et al., 2004).

In summary, identifying desire and willingness to donate again, improved quality of life for recipients and adjunctively for donors were shared, replicated, and reiterated themes throughout quantitative studies. Implementation of extended psychosocial follow up for living liver donors was identified as essential for good care. Questionnaires quantitatively designed as well as lack of open-ended questions significantly limited further exploration of themes important to donors. This quotation, cited by Green and Tones (2010) and attributed to Andrew Lang (1844-1912), asserted “He uses statistics as a drunken man uses lampposts - for support rather than for illumination” (p. 498). Lang addressed shortcomings of many studies in relation

to the research question about embodied experiences of living liver donors. Questions like “why would you choose to do this again? What are the benefits to yourself and to your recipient?” could yield more data and explore options for improved quality of life. Studies generating quantified data often failed to describe fully, living liver donor experiences.

A small number of participants reported decreased quality of life and psychological disturbance post donation. In four studies, DuBay et al. (2010), Erim et al. (2006, 2007), and Trotter et al. (2007) failed to include data about pre-morbid psychiatric evaluations, or pre-existing conditions prior to participating in living liver lobe donation. Participants explored self-generated important themes concerning phenomenon of feelings and experiences in two qualitative living kidney donor studies. This approach suggested qualitative research would yield richer data for this study’s research question.

Donor Selection

Few publications about donor psychosocial selection criteria and evaluation exist despite stressed importance of effective and standardized donor selection and counselling (Erim et al., 2008). Psychosocial and psychosomatic assessments for adult living liver donors have not, to date, been fully described or evaluated in the literature. Opening discussion to objective evaluation of donor candidates could enhance living liver donation. There is no single standardized assessment procedure among international health care centres. Listening to descriptions and impacts of donor experiences will lead to increasingly comprehensive pre-surgical evaluations based on values described by living liver donors.

In a study concerning overturned organ donation wishes by donor families, Sque et al. noted disjunctive moments created between the goals of deceased donor families and transplant teams (2007). In a convenience sampling of 26 family members, factors influencing donation

decisions in this multi-centre, quantitative study included a preconceived knowledge of deceased patients' wishes. Lack of understanding around the concept of brain death and negative feelings towards deceased patients contributed to perceptions of being surprised, pressured, or harassed about the decision to donate cadaveric organs (Sque et al., 2007). Resulting in loss of suitable cadaveric organs, families' misunderstanding, ambivalence, and strongly held beliefs led to impasse in communication and lost opportunities for organ donation.

In conclusion, there is no consistent, standardized assessment for living liver donors. This inconsistency negatively impacted objective evaluation of suitable donor candidates and intensified ambivalence surrounding selection of organ donors. Donors experienced confusion through lack of transparency in assessment processes. Ethical fallback to medical paternalism dismissed rights to patient autonomy, and did not enhance knowledge around the decision-making process.

Experiences of Living Liver Lobe Donation

Donors have complex reasons for stepping forward to donate; for some it is the active gesture of altruism itself; for others, there is a suggestion of improved quality of life for recipients and, by extension, easing of family burden for living liver donors. For others still, there is an opportunity to fulfill one's own needs and belong to the community of humankind. There is still much to be learned about donor decision-making.

Addressing the need for restitution by becoming a post hoc, non-traditional donor, Bryant, a nurse, wrote compellingly of obstacles she met during the donor pre-transplant assessment process (2008). In this narrative communication, Bryant spoke of her wish to anonymously donate a lobe of her liver as a tribute to her aunt, who died prematurely from organ failure. Alluding to altruism of donor families, and using descriptive nouns like greatness,

heroism, and strength, Bryant elided over personal need for reparation. Recalling suspicion and obstruction encountered with transplant teams, Bryant vividly described attempts to become an anonymous living donor. Suggesting the adoption of anonymous or directed living liver donation, Bryant concluded efforts could close the gap between the need and ability to provide usable organs (2008).

Shanteau, Harris and VandenBos (1992) reflected upon psychological and behavioural factors as roadblocks to organ donation. Shanteau et al. questioned why there are so few positive decisions to donate (1992). Expressed reasons for donation were mostly for others and altruistically oriented. Expanding the hypothetical rationale, Shanteau et al. stated, “people respond more positively to a persuasive communication emphasizing benefits to self rather than others. Apparently, altruistic motivations are easier to understand but self-orientated reasons are more convincing” (1992, p. 212). This influential article underscored a serendipitous finding, previously unreported in live donor literature. Replicating this finding, improvement in recipients’ health led to donor-derived benefits, and was identified as an important reason to donate (Feltrin et al., 2008). Considering embodied experiences of donors as valid reasons to donate, Shanteau et al., (1992) concluded donor-derived benefits were acceptable and important factors to consider in evaluation processes. Donation of a liver lobe to a seriously unwell person became an acceptable reason to consider living liver donation, releasing living liver donors from the burden of care. Considering the psychosocial impact on donors endorsed self-oriented reasons in donor decision- making processes (Shanteau et al., 1992).

Results of this literature review brought to light a gap in knowledge and understanding around complex issues of self- enhancement in living liver donors. Donor-derived benefits are valid reasons for becoming living liver donors. Alleviating burden of care for a sick person and

fulfilling a personal need to belong to humankind through tangible acts of donation were important considerations for potential donor candidates. Making restitution through organ donation is a justifiable offer, and not necessarily a sign of psychopathology. Enhancing awareness around embodied experience of living liver donors may increase our insight into donor motivation and influence knowledge around organ shortfall. Generating ideas for improved organ donation rates and patient-centred care, interest in research in the area of donor-derived benefits may stimulate open discussion and further future exchange.

Summary

Examined in Chapter 2 were seminal and current reviews related to embodiment, quality of life, ethical issues, and donor perspectives in living donor literature. Reflecting the focus of studies examined in this literature review also aided in the establishment of a foundation for thematic identification in this current study. Predominantly, quantitative studies did not adequately consider donor perspectives, strengthening arguments for richer portrayals of the lived experiences of living liver donation through synthesis of the living organ donor literature review.

Establishing valid methodology appropriate for this qualitative, hermeneutic phenomenological study is the focus of Chapter 3. Expanding on and including van Manen's method for exploring lived experience of living liver donation, this chapter incorporates a methodological approach, including population, sample size, inclusion criteria, data collection, based on van Manen's method for data collection and analysis.

CHAPTER 3: METHODOLOGICAL APPROACH

The purpose of Chapter 3 is to describe and delineate the method used in this study. Little is known about living liver donor experiences; therefore, exploring meaning surrounding participants' perception of the experience may significantly increase knowledge of this unique population. Lived experience is the beginning and end point of phenomenological research, with the intention to transform lived experience into a written articulation of its essences (van Manen, 1990). Phenomenology, with roots in philosophical tradition, is a way of thinking and interpreting peoples' life experiences. In this current study exploring donor experiences of offering a liver lobe and saving a life is suited to a qualitative method using a phenomenological approach.

Research Question

To date, living liver donation research has not been guided by participants' discussions of transplant related issues. Measuring life-altering experiences did not capture essences of the lived experiences of living donors. Quantitative research attempted to but neglected to fully describe rich and intricate emotional changes evoked because of surgical intervention. Characterizing simultaneous uniqueness and universality of experience, donor-led conversations guided exploration in interest of living liver donor phenomenon. Bringing awareness of the complexity of issues left unaddressed by solely quantitative research generated interest for this study. Turning towards participants' experiences, this qualitative, phenomenological study began with the research question: "What was the meaning of the lived experience of being a living liver donor?"

Theoretical Framework

Phenomenology

Phenomenological research has become increasingly important in describing and illuminating responses to nursing questions. An approach to human science inquiry, phenomenological methodology complements nursing philosophy, by understanding individuals as unique and exploring interactions with others and their world (Lopez & Willis, 2004). While phenomenological methods have much in common with other qualitative approaches, they differ due to roots based in the tradition's philosophical base (Cohen, 1987). Uncovering meaning in everyday experiences and seeking description of basic lived experience distills the essence of phenomenology.

Adherents of phenomenological philosophy differ in the exact nature of phenomenological interpretation. Major contributors to this philosophy consider the focus of phenomenology to be consciousness, human existence, or the very nature of being itself; moving away from objects and nature, toward exploration and understanding of human beings and their worlds (Giorgi, 2005). The intention of phenomenological researchers is to uncover, explore, and describe a phenomenon unique to study participants, and use this knowledge to shape future action (Van Manen, 1990).

Historical Overview of the Phenomenological Movement

Phenomenology diverges within various philosophical and human science disciplines, having different meanings and foci embedded within phenomenological philosophy. The phenomenological movement is principally divided into three phases 1) The preparatory phase, 2) the German phase, and 3) the French phase. "Movement" describes a dynamic philosophy

changing over time, highlighting shifting interpretations by diverse philosophers within phenomenological philosophy (Cohen, 1987).

Husserl (descriptive) tradition. Phenomenology became a significant movement in the 20th century, initiated in 1900 by Edmund Husserl. Designated as founder of the modern phenomenological movement, Husserl hoped to elevate the phenomenological method to the status of rigorous science (Walters, 1995).

Heidegger (interpretive) tradition. The phenomenology of Martin Heidegger is based on existential understanding of the person. The person living in the world and concepts of the world are inseparable and cannot exist in isolation from one another (Walter, 1995). Describing human experience includes perception of interconnectivity between the self and other in the world.

Researchers' own beliefs are legitimate parts of the research process, and are included in the method. Accepting interconnectivity of preconceptions and prior awareness of research questions is integral to the research process (Creswell et al., 2007). There is no bracketing of the researcher's experience, reinforcing concepts of interconnectivity between participant and phenomenon, researcher and participant, and self and other.

Hermeneutics. Like Husserl, Heidegger had a phenomenological method for his analysis of "being-in-the-world," a presupposition of prior understanding on the interpreter's part leading to overall understanding (Walters, 1995, p. 784). Heidegger argued interpreting a phenomenon was only possible if the experience had been previously understood and described by the interpreter (Walter, 1995). Although never having experienced the phenomenon, working alongside living liver donors placed this researcher in a unique position to explore phenomenon expressed by participants in this study.

The Lived Experiences

Van Manen. Phenomenologists seek to describe basic lived experience and the study of essences. Phenomenological research explores meaning in everyday existence, as “the fulfillment of our human nature: to become more fully who we are” (van Manen, 1990, p. 12). Van Manen (1990) described his approach as human science research, employing methods of phenomenology and hermeneutics. Van Manen believed phenomenology is a critically oriented action research approach (1990). Fundamentally oriented in pedagogical tradition, van Manen believed this approach to be relevant and applicable to researchers in nursing, psychology, and for other professions attuned to a need for phenomenological awareness of lived experiences (van Manen, 1990) and to use research as a change agent. The selection of van Manen’s human science research was intentional because van Manen’s hermeneutic philosophy and methodological approaches best suited the nature of inquiry into the lived experience of this previously under- researched population of living liver donors.

Avoiding predetermined techniques for data analysis remains a characteristic of phenomenological research. While there is not one set of fixed procedures, van Manen perceived hermeneutic phenomenological research in human sciences as interplay between six research activities (van Manen, 1984, 1990). This method begins by turning towards the lived experience through: 1) Turning to a phenomenon that seriously interests us and commits us to the world, 2) investigating experience as we live it rather than as we conceptualize it and, 3) reflecting on essential themes which characterize the phenomenon. Also included are 4) describing the phenomenon through the art of writing and rewriting, 5) maintaining a strong and oriented pedagogical relation to the phenomenon, and 6) balancing the research context by considering parts and the whole (van Manen, 1990).

Research Method and Design Appropriateness

Valuing exploration of the research question using a hermeneutic, phenomenological approach was congruent with this researcher's attitudes toward development of nursing knowledge. As a way of obtaining deeper understanding, nursing research requires methods of inquiry offering the freedom to discover richness of lived experiences (Allen & Jenson, 1990). Emerging from texts or other writings, phenomenological hermeneutic approach is essentially a philosophy about sensitivity to and interpretation of a particular phenomenon (Polit et al., 2001). Attending to sensitive issues with the freedom to uncover, reflect and interpret participants' perceptions of living liver donation justified the decision for use of a phenomenological approach for this current study. After review of various research approaches, phenomenology fits together with the exploration of the research question for this current study because hermeneutic phenomenology tries to attain a reflective understanding of the participants' lived experience (Merleau-Ponty, 1962).

Importantly, differing from other interpretations of phenomenological research methods, hermeneutic phenomenology does not require researchers to bracket their own experiences and preconceptions during the research process (Lowes & Prowse, 2001). True interpretation cannot exist when separation of self and consciousness occurs (van Manen, 1990). Interconnecting experiences between donor and recipient, and researcher and participant, especially self and conscious awareness of personal life experiences, served to enrich phenomenological understanding through mutual dialogue during interviews (van Manen, 1990).

Moving from an undefined to a precise understanding of data interpretation, analysis emerged primarily as a hermeneutic circle; described as starting in the present, a hermeneutic circle of interpretation moves forward and backward and never closes or ends (Allen & Jenson,

1990). This concept supported experiences of simultaneous positive and negative donor beliefs around embodiment, and highlighted complexity in grasping and interpreting donor concerns for this researcher.

Phenomenologists are interested in four aspects of lived experience: lived space, or spatiality; lived body or corporeality; lived time or temporality; and lived human relation or relationality (Polit et al., 2001). Further, hermeneutic phenomenologists consider human existence as meaningful due to peoples' conscious awareness of existence. Acknowledging an embodied sense of being-in-the-world conceptualized peoples' physical ties to the world through thinking, hearing, seeing, and feeling this bodily interaction (Polit et al., 2001). Using a hermeneutic phenomenological approach complemented exploration of living liver donors' experiences.

Design Appropriateness

Hermeneutic research is an exploration of the fullness of living; its ultimate aim is the fulfillment of human nature, "to become more completely who we are" (van Manen, 1990, p. 12). Van Manen described anything presenting itself to consciousness as potentially interesting as a phenomenon; a thing real, imagined, measurable or felt (1990). Asserting phenomenology aims at gaining deeper understanding of nature or meaning of everyday experiences, van Manen's hermeneutic approach (1990) guided this study by engaging researcher and participant with the research question. In phenomenological study, the principle data source is in-depth discussion, acknowledging researcher and participant as co-contributors (Polit et al., 2001). Bringing a methodological structure to human science research, van Manen's approach offered a structure to analysis by comprehensive data collection through shared conversation (1990).

The Lived Experiences

The intention for using van Manen's methodological approach in this current study was to explore the meaning, from a participant's perspective, of what it is like to experience being a living liver donor. Beginning with van Manen's six interrelated research activities provided a structure of constant interplay between the research activities. This methodological approach invited the researcher to investigate the experience as it is known to the participant, not how the researcher may understand the phenomenon (van Manen, 1990). Reflecting on material provided through audio taped interviews, transcripts and memos, the next steps included line by line review, reading the work as a whole and searching for common themes. Describing these themes can change through the next step of writing and rewriting about the participant's lived experiences with living liver donation. Linking interconnectivity of van Manen's steps guided interpretation of this study and is explored in depth in this chapter.

Study Sample

Sampling. All potential participants were women or men between the ages of 16 and fifty-nine. The rationale for this selection was the newly changed, minimum age to make autonomous medical decisions with a cut off age related to being an older, marginal donor. Participants had to speak and understand English. Importantly, all experienced the phenomenon of being living liver donors, had been interviewed previously about their suitability to donate and had undergone surgery to donate a liver lobe to a recipient. Coming from disparate backgrounds, all participants completed secondary school and some completed post-graduate degrees. All were able to fully describe the experiences of being living liver donors.

The physician and program nurse, both members of the living liver transplant team, approached potential participants to offer a letter informing him or her of this current study. Avoiding confounding factors of pain, rehabilitation, and return to work issues, potential

participants were required to be at least six months or longer from post-surgical intervention. Demonstrating interest in learning more about the study, potential participants gave permission to the team member to contact this researcher for initiation of phone contact. Participants were screened and recruited on the telephone, and an appointment was made to meet at the participant's convenience. Reviewing the purpose of this study offered opportunities to expand on questions and advised participants of the hour-long duration of the interview.

This qualitative study used purposeful sampling. Purposeful sampling is identification of a group of people who experience the particular phenomenon under study, and who are willing to share experiences with the researcher (Speziale & Carpenter, 2007). Using purposeful sampling in phenomenological studies with participants who shared unique experiences provided in-depth data relevant to the research question (Milne & Oberle, 2005). Sharing unique experiences of being living liver donors, these participants met the criterion for purposeful sampling.

Sample size. As Creswell, Hanson, Plano Clark and Morales (2007) suggested, several individuals who have had the same experience, or a sample of three to five participants is sufficient to provide rich descriptions of the experiences. This current study had a sample size of four participants and is congruent with qualitative research. While there are no established rules for sample size in qualitative research, size is a function of the purpose of inquiry, quality of participants, and the strategy used (Polit & Beck, 2006).

Adding to this concept, van Manen iterated descriptions of experiential accounts were never identical to lived experience itself (1990). This heterogeneous group of three women and one man, two of whom were anonymous donors and two directed donors, participated in this study. One participant donated twice, initially donating a liver lobe to a known recipient and later, a kidney to an anonymous recipient.

Inclusion criteria. Meeting criteria for this study as described previously, participants were male and female adults between the ages of 16 to 59 years, who spoke and understood English. Screening participants previously about their suitability to donate, all participants had undergone living liver donation.

Setting. Conducting this study at a large Canadian, urban, quaternary health centre increased participants' ease due to familiarity with the setting. Interviewed individually and face to face, three participants chose the health care centre as the interview setting. One participant selected the workplace boardroom as a preferred setting.

Consent

Consent process. Beginning the face-to-face interview, participants received further information about confidentiality and rights to refuse any questions, or withdraw from the interview at any time. Offering time to reflect on the decision or to continue later, each participant chose to proceed immediately. Participants were reassured personal choices to proceed or terminate involvement in the study would not affect any care received at the health care centre. Participants signed two copies of the consent form, witnessed by this researcher, and kept one copy for personal reference. Participants were informed the interview would be audio taped and all consented to this form of data collection.

Ethics. Research Ethics Boards at a hospital and Ryerson University Research Ethics Board approved this current study before the data collection began. Meeting potential candidates for living liver donation for in-depth interviews is an aspect of this researcher's work at the health care centre. Circumventing potentially compromised feelings about future treatment at the health care centre and thereby altering the integrity of this study, living liver donor transplant staff directly approached potential participants instead of the researcher. Living liver donors have

routine medical follow-ups after donation. Regular appointment times provided opportunities for team members to approach the donors and speak with them about this study. Informing members of the living liver transplant team about the study's purpose garnered support for approaching potential participants for recruitment. Agreeing to speak directly to participants, team members circumvented potential ethical impasses. Expressed interest allowed team members to contact this researcher to screen and supplement additional information for potential participants.

Reassuring participants that decisions regarding involvement in this study would not jeopardize future care served to further support adherence to ethical considerations. Conducting interviews in a private office ensured rights to privacy, discretion, and anonymity for participants. Replacing names with coded numbers guarded anonymity, and participants received information about their protected position. Data was collected using audiotapes, transcripts, and notes, all were kept in a locked drawer. Standardized adherence to regulations for data storage after study completion offered reassurance about confidentiality for participants. To meet regulations, erasing of audiotapes and shredding memos and transcriptions at the appropriate time, in accordance with ethical regulations will occur. Following stipulated requirements of the research ethic boards, the screening log must be maintained and locked for a period of 10 years.

Participants were at minimal risk throughout this interview process. However, the personal nature and meanings of the lived experience, embodiment, altruism, and self-reflection had potential to create some distress for participants. Reassuring rights to refuse, answer or elaborate on interview questions increased comfort and choice for participants. Alternative emotional support if necessary, was offered to the participants with colleagues from the

psychosocial department. In lieu of a financial remuneration, participants received \$10.00 vouchers for Tim Horton's coffee.

Data Collection

Scheduling 45 to 60 minutes for this semi-structured interview allowed participants to determine the length of time; however, each participant took the full hour to complete the interview. Interviews ended when participants acknowledged there was nothing further to add. The interviews were audio taped and tapes were transcribed within one week of the interview by a reliable transcriptionist recommended and used by researchers at the health care centre. Replacing names with coded letter and number combinations, and alerting participants of their protected positions when study results were presented enhanced anonymity. Further, informing participants the audio-taped interviews and collected data were secured in a locked drawer offered increased protection and confidence in identity protection.

Each interview with participants was conducted privately and in person. Participants decided between being interviewed in a setting of their choice or an office at the health care centre. Choosing to keep the interview questions open-ended, and not reading from a prepared script as outlined in van Manen's qualitative methodological approach ensured participants the opportunity to lead the discussion.

Facilitating discussion of open-ended questions clarified comments and allowed expansion of personal experiences and donor-led discussion of the participant's experience. Beginning with a single, open-ended question, each semi-structured interview started with an overarching question: "What is it like to be a living liver donor?". Additional questions included "What types of factors may have contributed to the decision to donate a liver lobe?" and "If you

are comfortable, please tell me a bit about your personal beliefs around the meaning of your life”.

Meaning is multi-faceted and thickly layered, and cannot be absorbed by single definitions (van Manen, 1990). Human science interpretation can only be conveyed through organized narratives. Involving a process of reflective appropriation and clarification of structure in lived experiences permits insight into essences of a phenomenon (van Manen, 1990). Writing about participants’ affect and mood after interviews assisted reflection on emotional congruity or disjunctive moments. Memos provided a means to further describe, analyze, and interpret behaviours such as statements, non-verbal cues, and gestures. Reflecting on expressions of lived experiences led to reflective analysis of structural or thematic facets of experience (van Manen, 1990).

Taking memos after the interview brought subjective awareness for reflection on the feeling tone in the room (Speziale & Carpenter, 2007). Notes also served to bring awareness of possible feelings related to counter-transference experienced through interview question responses. Assisting as a reminder of the inter-subjective tone during the interview in this current study, rereading memos helped this researcher to identify personal information; the way the participant was dressed, the ease of relational styles, gestures and even impressions of truthfulness during the interview. Memos were helpful to write about a sense of personal engagement or discomfort in the stories of participants’ descriptions of their experiences being living liver donors. Evoking personal discomfort for this researcher was one participant who insisted on showing multiple transplant-related tattoos. At times, occurring in the context of the nursing role as the psychiatric clinical coordinator for the Multi-Organ Transplant Program, patients had previously shown scars and tattoos. On this occasion, uncertain how to respond as a

novice researcher in this setting, there was awareness of discomfort about how to respond in this unfamiliar role. Reviewing personal memos allowed this researcher to explore both the participant's insistence and understand the awkwardness experienced through a personal moment of sharing.

Preparing for any potential difficult emotional moments generated throughout the interview, participants recognized opportunities to pause and move through sensitive moments. Offering extra time to think, continue or terminate the interview reassured participants of respectful sensitivity during each discussion. Recognizing the potential for emergence of overwhelming emotional material, participants felt secure as the discussion could be terminated or returned to at any point. No difficult moments occurred with any participants in this current study.

Data Analysis

The aim of qualitative research is to help understand what experiences are like for participants; to describe, understand, and value perspectives and feelings of people, and to understand how people make sense of their worlds (Speziale & Carpenter, 2007). Analysis must be scrupulous to ensure what the informant said, if interpretation is correct and as participants meant; therefore, the analysis follows a cohesive and consecutive pattern. Reflexive telling, retelling, and interpretation of experiences established an acute sense of meaning, reflected facets of imagination and connection to the readers' own lived experiences (van Manen, 1990).

Reflecting iterative effort remained a central characteristic of phenomenological study. Supporting processes of immersion in data, reflective engagement with data and generation of rich description attuned readers to deeper fundamental structures embedded within human experience (Thorne, 2000). This cyclic process of asking questions, seeing questions appear

through transcriptions, and confirming meaning in adherence to van Manen's methodological process were all essential steps in data collection for this study. Attending to descriptions of experiences as living liver donors, van Manen's Heideggerian, phenomenological research activities guided data analysis. Identifying major themes, textual descriptions, and structural descriptions revealed essences of the phenomenon (Creswell, 2007).

Basing this current study on van Manen's philosophy explored what is like to be a living donor through his approach to data analysis. Highlighting vibrant interconnection between six research activities began with steps turning towards the lived experience. Van Manen (1990) described the reduction of hermeneutic phenomenological analysis to a fundamental methodological structure with ambivalence, but maintained all research activities should not be perceived as separate but interwoven with one another (1990).

Van Manen's research activities (1990) included identifying gaps in understanding of a phenomenon; in this current study, gaps in the transplant literature included the lived experiences of living liver donors. This lack of reported interest initiated consideration in exploring van Manen's research methodology because of the interconnection of the research activities. Secondly, van Manen described phenomenology as a type of research as a poeticizing activity, in that "it tries an incantative, evocative speaking, a primal telling wherein we aim to involve the voice in an original singing of the world" (van Manen, p. 13). Van Manen continued to support artistic forms as sources to enhance the expression of language (1990). The researcher could transform, interpret, or poeticize ordinary human experience in infinite variety. For this researcher, poetry is the accessible connection to truth sometimes beyond conversational moments, and can facilitate identification of emotions for many people. Furthering exploration of

donor-led interests through hermeneutic, phenomenological inquiry substantiated the use of van Manen's methodological approach.

When approaching this current study, van Manen's Heideggerian, phenomenological research activities guided data analysis. Van Manen's approach to phenomenological research offered opportunities to both describe and interpret meaning of the lived experience of living liver donors. Discerning interconnection as an interplay between six designated research activities began with steps turning towards the lived experience. Reducing hermeneutic phenomenological inquiry to data analysis procedures had potential for misinterpretation or lost intention of meaning. Acknowledging these pitfalls, van Manen (1990) established a functional methodological structure for interchange between research activities. Citing these research activities demonstrated an in-depth interconnectivity of the steps or stages for guiding data analysis in this study of lived experiences of being living liver donors.

Utilizing these activities provided structure for this current study, firstly turning to a phenomenon that seriously interests us and commits us to the world (van Manen, 1990). Building on van Manen's first step, experience from this researcher's clinical work and subsequent literature review demonstrated a lack of qualitative research concerning reasons why people donate, what the experience is like before, during and after the donation experience. Pursuing this topic was interesting clinically, and had enormous potential to explore the possibilities for further understanding of why people choose to donate.

The second step, investigating experience as we live it rather than as we conceptualize it (van Manen, 1990), flowed from the first. Evoking curiosity about the experience of living liver donation as it is, rather than how it is perceived, was only accessible through meeting and exploring the meaning of being living liver donors with in-depth, one-to-one interviews. The

third interconnected step was reflecting on essential themes that characterize the phenomenon; described through transcripts, audio tapes and notes.

Van Manen suggested three processes for isolating thematic statements embedded within the six methodological steps (1990). Initially, reading the transcripts and listening to the audio tapes ensured faithful precision of the collected data. Absorbing the transcripts through initially reading them as a whole allowed for an overview into the meaning of each participant's lived experience of donation. Listening to the audio tapes, re-reading transcripts and reading memos offered an initial opportunity to initiate identification of themes using van Manen's holistic perspective (1990).

Secondly, listening to each audiotape and writing recurring expressions on a sheet of paper facilitated the isolation of themes gathered from participant interviews. Expressions highlighted through identification with repetition, common usage and direct quotes captured the essence of the experience. Phrases were placed under headings with similar phrases, further refining the thematic analysis.

Finally, the last step for uncovering and isolating themes in this current phenomenological study was to review each transcript line-by-line, examining not only the meaning of the words, but the larger, essential experience of the participant's understanding of being a living liver donor. Reading memos written after each interview, reflecting on and imagining the ways each participant described the experience allowed the exploration of themes to emerge.

The following fourth and fifth steps were describing the phenomenon through the art of writing and rewriting while maintaining a strong and oriented pedagogical relation to the phenomenon (van Manen, 1990).

The Lived Experiences

Reading what the participant said, imagining aspects of a theme (van Manen, 1990), reflecting on personal notes and transcripts, writing about themes and discarding material while maintaining focus on the lived experience of living donors proved the most challenging aspect of this methodological approach. Refocusing on participants' experiences, bringing awareness to personal bias and interpretation and uncovering themes were activities to maintaining methodological focus.

Finally, the sixth stage returned to balancing the research context by considering parts and the whole by reviewing the work line-by-line, holistically, and as a representation of the thematic truth for participants as determined by van Manen (1990). Applying theory to this current study is an explanation of how van Manen's research activities informed this study on the lived experience of living liver donors. Proceeding in the following section is a detailed description of each step of the six research activities and how van Manen's methodological research activities guided this current study.

A phenomenon that seriously interests us and commits us to the world. Attuning to comments about profound life-altering experiences following living donation in the clinical setting led to questions about the meaning of the experience for patients. Discussing the emotional impact of donation in this clinical setting initiated awareness of the unexplored experiences of living liver donors. Opening to the possibility of a surgical intervention may have a multiplicity of meanings for donors and oriented the researcher to the previously ignored phenomenon of the experience of living liver donation. Participants appreciated the opportunity to talk about their experiences of being living liver donors. Turning to the second step in van Manen's functional methodological structure for data analysis (1990) included:

Investigating experience as we live it rather than as we conceptualize it. When reviewing previous transplant literature asking for quantifiable answers to predetermined questions, a phenomenological approach using open-ended questions allowed for expansion of topics important to participants. The overarching question for this current study was “What is it like to be a living liver donor?” Other questions included in the interview were “What types of factors may have contributed to the decision to donate a liver lobe?” and “If you are comfortable, please tell me a bit about your personal beliefs around the meaning of your life.” From these questions, participants explored the meaning of living donation as a phenomenological experience. Further, expanding on the process of van Manen’s analysis (1990) included the following step to interpret and organize statements into central themes.

Reflecting on essential themes that characterize the phenomenon. Writing and reviewing memos after each interview, reading transcripts as a whole, highlighting key words or phrases, and line-by-line analysis of transcriptions facilitated an identification of themes (van Manen, 1990). Shared words and commonality of expression or ideas created a broad understanding of the phenomenon of embodiment with living liver donors. An essential step in van Manen’s approach is the art of writing and rewriting (1990). Allowing for development of ideas through an iterative writing process increased understanding of the phenomenological process and the content of participants’ statements. Offering objective analysis of the transcripts, peer reviews and meeting with thesis supervisors were essential aspects to reassess data and identifying themes.

Describing the phenomenon through the art of writing and rewriting. Describing the phenomenon of living donors’ lived experiences required multiple attempts to understand, define, and interpret participants’ statements. Interpreting and redefining comments and passages

in the transcriptions proved to be a challenging facet throughout this current study. Revealing assumptions through the process of writing and rewriting was an essential aspect of this research activity. Writing about participants' experiences also offered the opportunity to reflect on each phrase and its meaning. Van Manen asserted the goal of phenomenological understanding is to gain knowledge and translate that knowledge into action (1990). Linking methodological structure to the research activities generated action-oriented research.

Maintaining a strong and oriented pedagogical relation to the phenomenon. Van Manen believed phenomenology is a critically oriented action research approach (1990). Deepening thought through hermeneutic phenomenological cyclic reflection changes thinking, and change develops from reflective introspection. Leading to action, a focus in pedagogical research evolves from an informed opinion and can be demonstrated to others (van Manen, 1990). Describing the lived experiences of being living liver donors for the first time, through the words and ideas of participants, offered an opportunity to explore transplant perspectives related to the meaning of donation and potential changes in current living donation policy.

In most North American living donor transplant centres the standard assessment process, including psychosocial interviews, rely on traditionally paternalistic medical models, conservatively erring on exclusion of potential donors to protect the potential donor's physical and emotional well-being. This current study explored the experience from donor perspectives; while the sample was too small to generalize any findings, participants raised valuable issues concerning current assessment and psychosocial support post donation. These comments will be offered in Chapter 4. Finally turning to the final sixth step in van Manen's (1990) research methodological approach was:

Balancing the research context by considering parts and whole. Human science is concerned with meaning and interpretation of meaningful articulated themes. Reading and rereading transcripts established awareness of entering into experiences described by participants. Broadly discerning key statements and then reading the script line-by-line revealed emergent themes (van Manen, 1990). Creating balance was necessary for this novice researcher because of the difficulty of shifting focus from a fixed perception of an identified theme while losing more subtle statements about living donor experiences. Facilitating clarity with this final step was peer review meetings with committee members to refocus on the meaning of participant statements for identification of the thematic texts.

Van Manen (1990) also suggested the personal involvement and investment by participants and researcher using these methodological approaches may have positive lingering effects for both members of the research study. Reflecting on the final stage, iterative attempts to understand the experience of being a live donor through in-depth interviews with participants characterized thematic analyses of this phenomenological study.

Assumptions of the researcher

Describing and interpreting the meaning of liver lobe donation in the context of the participants' lived experience was the first assumption of this current study. The study expanded on existing literature in living organ transplantation, broadening previously unexplored understanding of participants' feelings and attitudes surrounding donor experiences. The second assumption pertains to living liver donor participants who shared experiences of being living liver donors. These donors were all eager to participate, previously never having been asked by a member of the health care team to reflect about living donation. The third assumption is selecting a hermeneutic, phenomenological, methodological approach to explore this phenomenon. The

interpretive approach is necessary for understanding the living donor experience. Understanding this context ultimately has relevancy for clinical practice in transplantation. A critical hermeneutic framework enabled exploration of an experience previously underreported through a purely descriptive approach (Svedlund, Danielson & Norberg, 1994).

Phenomenology as a type of research is a poeticizing activity, in that “it tries an incantative, evocative speaking, a primal telling wherein we aim to involve the voice in an original singing of the world” (van Manen, p. 13). Van Manen continued to support artistic forms as sources to enhance the expression of language (1990). A fourth assumption is the author can transform, interpret, or poeticize ordinary human experience in infinite variety. Poetry allows interpretation of intense and at times inexpressible feelings, sensitively attuning to unique experiences embodied in living liver donation. Finally, the assumption of researcher bias reflecting personal tone through wording of questions may occur and unduly influence interpretation of the data (van Manen, 1990).

Rigour. Trustworthiness, rigour, and authenticity of data in qualitative studies are necessary for good practice; however, debate continues regarding evaluating the strength of analysis. The process of writing memos after each interview in qualitative studies supports rigour may compare with the ‘validity’ construct in quantitative studies (Speziale & Carpenter, 2007). Writing detailed notes after each interview and transcriptions contributed to rigour and authenticity of collected data. As van Manen (1990) described, human science research is a form of writing, and creating phenomenological content or writing is the object of research processes.

For van Manen, writing is self-conscious, deliberately bringing awareness to inner and outer worlds, perceiving subjective self against objective self (1990). Writing and reflecting on notes and data analysis ensured rigour and authenticity of collected data through the process of

constant examination of personal bias, notes and transcripts. Reflecting on believability of the study was the use in this current study of directly transcribed quotes from the participants; these quotes provided the opportunity to hear their voices and re-enact the original experience and meaning.

Authenticity and credibility. Integrity, referring to reflexivity of this researcher examined sources of bias as being an investigator and a nurse practicing in the living donor program included the role of participant in phenomenological research (Milne & Oberle, 2005). Meeting regularly with thesis supervisors served various and specific purposes and important to maintaining focus. Reviewing copies of transcribed interviews allowed for confirming or conflicting interpretations of identified themes. Reflecting on accurate written interpretations of interviews through regular committee meetings, individual meetings with thesis supervisors, and email and phone discussions ensured adherence to peer review and increased the integrity of this current study (Milne & Oberle, 2005).

Dialogue about perceptions and bias brought awareness of congruency in truthfulness and interpretation of identified themes. This study changed directions at least twice during the imagining and rewriting stages using van Manen's methodological approach. As an example, once while the researcher described the central theme as being "motivation", a member of the committee reminded the researcher the purpose of hermeneutic study was to discover the participants experience with what was actually being experienced and not predetermining the outcome. On another occasion, in a committee meeting, one supervisor talked about the concept of "embodiment" revealing a previously unconsidered theme, identified through discussion and re-reading of transcripts.

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Journaling was a useful medium for reflection on subjective impressions parallel to research activities. Establishing trust and sharing between participant and researcher through lengthy, open-ended interviews was a characteristic of this qualitative research study. Assuring qualities of authenticity and credibility in qualitative research was important to honour participants' trust through maintenance of self-awareness throughout the process.

Learning to conduct a phenomenological interview included initial mistakes, recognized through post interview journaling. Leaving the first interview with one participant, there was a sense the interview had ended because of time factors; the participant seemed engaged and wanted to continue talking. Journaling later in the day, this researcher reflected on personal anxiety about "not bothering" the participant and going over time. This researcher expected the interview to last an hour and was concerned about going over the anticipated time limit as outlined in the consent.

Despite extensive interview experience, the interview terminated prematurely due to lack of trust in the process. Fortunately, the participant did email later in the week, as invited, to include further data that enriched the study. Recognizing this anxiety permitted the next interview to flow more easily, and allowed the interview to end in a more participant-directed way. Journaling about this event allowed the researcher to recognize a methodological error. Iterating awareness of van Manen's methodological approach reminded this researcher to continually be self-aware and present to flow of an interactive phenomenological study (1990).

Summary

Expanded on in Chapter 3 were research methods based on van Manen's hermeneutic, phenomenological approach to understanding lived experience. Including discussion of research design, sampling, consent and ethics, confidentiality, rigour and authenticity, data collection and analysis resulted in a structured working framework. This method supported exploration in perceptions of the lived experience for living liver donors. Presenting participants' descriptions of living donation interpreted through data collection and analysis is the focus of Chapter 4, with an emphasis on donors' quoted responses to interview questions.

CHAPTER 4: RESULTS

Summarized in Chapter 3 were an overview of phenomenology and a brief description related to the three phases of phenomenological approaches. Choosing to interpret this study from a hermeneutic phenomenological perspective, and using van Manen's human science, pedagogical, methodological approach, added richness to experiential descriptions in the lived experience of living liver donors as described in Chapter three .

Expanding upon relevancy to the literature review and interview questions in connection with the introduction of interview data is the focus in Chapter four. Concluding with summation of outcomes from this study, Chapter four highlighted living liver donor reflections through use of quotes culled from participant interviews. Reflecting on the interview questions, one participant later sent an email, also included in the quotes.

Results

Attuning to this phenomenological qualitative study, the purpose was to explore and expand knowledge about the lived experiences of living liver donors. This group was able to describe expressed or tacit considerations around experiences of stepping forward for living organ donation.

Replacing the names of participants with a combination of coded letters and numbers maintained participants' anonymity in this study. Participants were A1, A2, A3 and A4, related to the order in which each was interviewed. As well, protecting anonymity by replacing every person named in the interviews by participants with "Recipient" was a conscious editing by the researcher. Including additional information from an email emphasized the positive effects of the interview experienced by one participant and permission was given by the participant to include the experience in this current study. Otherwise, gathering data from transcripts and audio tapes,

all quotes were written in this study exactly as spoken by participants. Including quotes from the participants enhanced exploration of the meaning of being living liver donors.

Themes

Identifying themes is a purposeful way to uncover meaning and begin to understand a phenomenon (van Manen, 1990). The aim of this current study was to explore the meaning of being a living liver donor, to understand how the decision to donate evolved, to discover the origins of the desire to donate with participants in this study and the impact of the decision in terms of experiences post donation. Discovering themes, through insight and revelation has origins in the desire to make sense of an experience (van Manen, 1990). Balancing the research context by considering parts and whole, van Manen (1990) argued human science is concerned with meaning and interpretation of meaningful articulated themes. Establishing awareness of entering into experiences described by participants, generally discerning key statements and then reading the script line-by-line revealed emergent, central themes (van Manen, 1990).

This process began with reading the transcripts initially as a whole providing an overview of the meaning of each participant's lived experience of donation. Secondly, listening to each audiotape and writing recurring expressions on sheets of paper initiated the process of thematic isolation. Highlighting expressions through identification with repetitive, common usage and direct quotes captured the essence of the experience and refined the thematic analysis. Finally, uncovering and isolating themes through line-by-line reading, explored not only the meaning of the words, but the larger, essential experience of the participants' understanding of being a living liver donor (van Manen, 1990). Reading memos written after each interview, reflecting on and imagining the ways each participant described the experience allowed for the emergence of

themes. As the research progressed, two key themes emerged: embodiment and ethical responsibility to one another.

Using van Manen's methodological approach (1990), identification of the two themes incorporated several facets distinguished through repetition of key words or phrases. Subsumed under each of the two themes, embodiment and ethical responsibility to one another were aspects of the identified themes. Clustering repeated phrases and concepts together into facets of the theme led to the recognition of thematic identification. Revealing two key themes, each theme possessing several interrelated facets, guided increased understanding of the phenomenon of the lived experience of living liver donors.

Incorporated into the key theme of embodiment, one facet of shared understanding was participants' expressions of living donation as a never-ending experience. Most participants stated they began the process without any preconceived idea of the transformative and ongoing life changes offered by living donation. Pointing out the ongoing nature of donation with this first question, A1 remarked,

I realize that maybe this journey is never going to be over. On a regular basis I'm reminded of it. It's just confirmed ... everything that I always was. Maybe it just intensified everything that I already was. I'm still learning more about myself because I did this.

Addressing self-perception and perceptions of others around living liver donation, A2 also reiterated living donation as an ongoing and vibrant experience. Surprising to A2 was the ongoing, emotional embodiment of the donor experience, even several years after the surgery and recovery period. A2 spoke of physical representation in daily reminders of her donation experience, asserting,

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This gets emotional. I can't think of a greater expression of love. Physically, it's like it never happened although I really hate it when people say it's over and it's like it never happened, because I don't think that people understand my life, forever, is different. My mom's really angry, just like, "You're not spare parts," and my sisters are kind of like "Why would you go and do that?" I have a shower, I have this massive scar that will forever remind me, and I'm proud of that scar, and for me it's an "L". If I look in the mirror, it looks like "L", "L" for love, that's what I tell everybody. It has helped define me in a very profound way because it says I'm willing to do whatever I need to for the people I love.

Choosing to share the donor experience or remain private was another facet of the theme of embodiment, shared by participants. There was expressed conflict whether showing the scar to others might be perceived as bragging or looking for sympathy. A1 discussed an incident demonstrating the personal meaning of being scarred or having a scar is a significant identifier of living liver donation. Surgical scarring became a symbol of the ongoing, embodied donor experience. Talking about the scar, A1 referred to an incident with A1's dragon boat team and the dilemma of self-revelation about being a living donor.

I don't go around telling people, "Hm, this is what my scar's all about," so people notice it but they're too polite to ask, and I'm sure my dragon boat coach has seen it a million times and too polite to ask, he never knew. I was helping one of the guys put his canoe away and I looked on his bumper and he had the green ribbon so I said, "You've got the organ donation ribbon!" and he said, "Yeah, I coach a team that's nothing but donors and recipients." I said, "Okay, well, now I'll tell you: I'm a liver donor." I hesitated because it's almost like you're bragging, but

once I knew... I felt comfortable to say because now we have something in common. Coach came over and hugged me. This 63 year-old man I've known for a year and a half hugged me and said, "Oh, you're such a fine person. I'm proud to know you."

Supporting this facet of visibility and disclosure of an embodied experience in living donation, A2 commemorated the living liver donor experience with body art, transforming the scar into an object of beauty. Using images of a green ribbon, initials of the health care centre and a butterfly, A2 drew upon the universally identifiable transplant symbol for transformation. Incorporating the original surgical scar, the tattoo included A2's donation date. Showing the tattoo, A2 stated, "I have two tattoos. I have this bumper sticker; it's a bumper sticker thank you." A2 included further remarks on the meaning of donor scars. Referring to an incident in clinic, A2 offered support to a new donor. Showing a recent living donor A2's healed scar helped the new donor connect through shared experiences.

Emerging from all the interviews, despite participant gender or the reality of actual parenthood was another facet of the theme of embodiment. Reflecting on birth metaphors and creation for new possibility in life, A2 considered the parallels between being a liver lobe donor and motherhood. A2 demonstrated self-awareness when describing her ambivalence about giving life through birth, stating,

(With) challenges growing up, I kind of took on a maternal role, and just by the fact that naturally I'm maternal. I guess as a woman you're mature, want to prepare to have kids and once you've had kids you've fulfilled some grand destiny. I've never felt that. I've always felt that if you make the world around you

a little bit better, if you help to ease somebody else's pain, then you've fulfilled your purpose and destiny. Maybe I'm helping create that world.

A3 reiterated the importance of this aspect of embodiment stating the donation of a liver lobe positively impacted previously delayed decisions to pursue parenthood. After living liver lobe donation, A3 began fertility treatments as a result of increased capacity to perceive hope and a future of happiness in life.

Exploring comparisons between physical birth and metaphorical birth, A4 considered the trajectory of life, moving from a career in business through unexpected life changes, post donation. Discussing this aspect of evolving self-creation, A4 expanded on rebirth as a facet of embodied experience of living donation. Contemplating transformation from previous indirect care of others led A4 towards unanticipated vocational changes and the creation of a new identity. Studying at the time of the interview to become a massage therapist, A4 remarked,

It's a continuum... in the sense of security, what I was doing was protecting people, in a sense, remotely, at a distance, indirectly. And then I became a minister. And one of the things, I started rereading the Bible, the gospels and it hit me like a ton of bricks, things I've been missing all along... the integration really never capture my awareness before... the number of times the stories of Jesus healing people through well-intentioned touch. I think Christianity is a religion of healing in a lot of senses, and it's not just the body of the beggar, there's a spiritual healing that happens, and dispelling of demons, literally and figuratively. To be a healer in my language being kind of the primary instrument of healing, I don't see myself in that role, really, not at all. But being a participant in healing process, I like it. I like it.

Identifying another facet of the embodied experience of living donation was personal transformation. Searching to make sense of this experience, A3 opened the discussion to speculate about donor-derived benefits. This theme resonated with all participants, whether donation was directed or anonymous. Most spoke to simultaneously held feelings of enhanced connection to self, others, and mutually derived benefits. A3 articulated the experience of donor-derived benefits, saying,

It's so much more than going in for surgery and recovering, you can go in and have, let's say, open-heart surgery, and it's just to fix yourself. You go and be fixed and then go back to life. I think this is so much more than that, and yet, what is it? I mean, that really is what it is. I went in healthy, I had a surgery, I recovered, I'm completely normal, back to normal and yet it's not. I really don't know how to define it. Maybe because it's because it did...someone benefitted from it, versus I needed it done for my own wellbeing. But I benefitted from it. I benefitted as much as my (Recipient) did. (Recipient) got to live and I got to have my life.

Donor-derived benefits arose easily and spontaneously while interviewing participants. Seeking clarification of meaning through opportunities to initiate and explore this topic acknowledged previously ignored aspects of living liver donation. Discussion of donor benefits was unanticipated and emotionally powerful for both participants and researcher.

Supporting this finding, A4 also spoke about serendipitous and unexpected donor benefits since becoming a living donor, disclosing,

(Prior to transplant) What does a fish know about the water in which it swims? And I guess I never thought about myself as being depressed and anxious, and I still don't, but I do notice since I've donated my organs that I don't seem to be as anxious

anymore, I just seem to be a happier person. I don't find myself being more critical of people when they are complaining, but I think maybe I'm even a little more sensitive than I was before about their struggles.

Continuing with two interwoven subjective and objective observations about donor-derived benefits, A4 examined an additional facet of the theme of embodiment in living liver donors. Commenting further, A4 said,

...But it is a transformative experience for me. How do I manifest that? I seem to be freer, I seem to be happier. And whether I can directly relate that- I don't know why that is – but I'm less nervous, I'm less self-conscious, I'm just a clearer person. My wife thinks I'm a better communicator, I'm a happier person. I don't have grumpy moments like I used to. People (say) "You've changed."

Balancing simultaneous held feelings towards experiences of living liver donation, participants cognitively understood donation experiences as a surgical intervention, while sensing donation as an emotionally transformative experience from one state to another. Giving voice to experiences of being living liver donors, participants described profound emotional, attitudinal, and life changes. Identified in words and stories, participants' experiences of embodiment evolved in relation to expressed meaning of being living liver donors.

Addressing another facet of the embodied experience of living donation, participants spoke of the triggering event in the ability to donate and the immediately identifiable "gut response" of choosing to donate. Participants' admitted the experience "felt right" from the onset, and only afterwards reviewed responses through self-reflection and information gathering. Alluding to a sense of internalized self-awareness A3 would donate, A3 celebrated an ability to contribute to life for the recipient, saying,

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I felt like we were being led down the path, that this was an option and we should take it. Yeah, this is the way it was supposed to be. So, for me, it was never an option.

Even if there had been a risk to me, I would have done it, because to me it was worth the risk and it wasn't much of a risk. I don't know that I would be a living donor for just anyone, but for certain people I would do it without a second thought. You know, maybe it's just wishful thinking, I don't know, it feels more than that. Like it was... we just weren't ready to be done...we're not going to lose (Recipient). And we might not have lost (Recipient) anyway but I just had a feeling this was how it was meant to work out.

Responding immediately to calls for help, A4 then tempered initial responses of offers to donate with self-inquiry and discernment. A4 delivered several insights, saying,

It feels wonderful, a wonderful feeling. Yeah, I feel very privileged and very blessed. A lot of people are not able to do that (donation). So the liver donation happened in 2008. I found out, just through a church bulletin, that somebody needed a liver transplant and if anybody would be interested in finding out more about it, get in touch with the pastor. So I did that day and two weeks later I was transplanted. I'm a person of prayer, and when I saw that ad in the bulletin I took it home, looked at it a few times, read it, and I thought, "Well, this really does feel right. There's something about this." I'm going to put myself forward because it really did feel like a genuine impulse, something from within me to do. It seemed to be a way of practicing what I preach, and this (act of donation) would be a way to embody that.

All participants spoke of mixed emotional reactions from others, including comments from health care professionals, when discussing plans for donation, or informing people post

donation and recovery. Stepping forward to donate, these varied reactions impacted both positively and negatively on participants' relationships with others post donation. Curiously, no participants swayed from the decision to donate, supporting the embodied knowledge of doing what "felt right".

None entered donation blindly, but reported additional reflection of turning inward toward embodied self-knowledge as guiding principles in donation decisions. Despite frequent negative comments about irrationality and unknown health risks in the future, these remarks had little effect in donors' decisions. Citing examples of health care providers' attempts to dissuade donors beyond informed surgical risks and benefits demonstrated assumptions of medical paternalism as best for patients. Exploring factors lead to decision-making, donors trusted embodied intuition for best personal choices.

Participants identified another facet of the theme of embodiment in living liver donation; the emotional and often negative reactions from family, friends and identified transplant team members. Addressing emotional tones present during interviews, participants were baffled, amused and saddened by others' perceptions of living liver donation. A3 commented,

I was a little shocked, actually, at a couple of their reactions from people when I told them (Recipient) needed a transplant and that I was donating, and then some people just... crashed. Now, they weren't close friends, they were relationships that dwindled over the years, and I think that was almost the final nail in the coffin, it was like they just didn't know. There's one friend in particular who I've known my whole life, was very hurtful. She never came. She finally sent an email a month and a half later saying, "I hope you guys are alright."

The Lived Experiences

Expressing dismay about negative reactions from friends, family and others, participants shared experiences about disclosing donation. Responses were often value-laden, reflecting commonly held misperceptions about living liver donation. A1 discussed reactions to her anonymous donation as negative. Although A1 never swayed from donating, A1 described comments as potent and difficult to hear, reporting,

There was fallout with my dad, he gave me nothing but aggravation, he didn't want me to do it, he never said, "I'm proud of you," or "Good for you." He said, "For all you know you're taking fifteen years off your life" and every time he saw me stick that heparin needle in my thigh he would clench his jaw. He never said anything supportive. He came in the hospital, which really surprised me, but he's never shown admiration or support, so very different reactions from my mum and stepfather.

Discussing the experience of donating a liver lobe and later anonymously offering a kidney, A4 met with varied responses. Speaking at length with A4's priest, several other priests, and A4's significant other, A4 discussed the process of prayer and self-inquiry, saying,

A few people thought I was nuts. You know, some people, friends said once is enough, I got that response, but the same impulse, so to speak, that helped me go through the liver donation, it carried me through the kidney donation. I did question it, I tried to criticize it, the impulse and so forth, and every time I kept coming back to this is the right thing to do. Analyze, you know, was I doing this for myself, was I doing it for others, what's the motivation, what am I getting out of this, what am I doing. You know, so I looked at it from a number of angles, and I really wanted to understand it, to the best of my ability.

Citing incidents of medical paternalism previously reviewed in living kidney and liver donor literature (Surman et al., 2005), several participants reinforced descriptions of negative reactions from health care professionals. Encountering instances of medical paternalism within the transplant program was also surprising for A1, mentioning,

Well, even the transplant surgeons...which one did I meet with? I don't remember his exact words but he came right out and said, "I can't imagine why anybody would do this. We think you are crazy." They really do make an effort to talk you out of it, because they want to know you are positive, that there is not a doubt in your mind, and they are very honest about the risks.

The aim of this current study was to explore the meaning of being a living liver donor through discovery of themes in an effort to gain insight and make sense of an experience (van Manen, 1990). Subsumed under the first theme of embodiment were several facets contributing to recognition of the theme. Possessing several interrelated aspects, embodiment, as a theme, increased understanding in the phenomenon of the lived experience of living liver donors.

Facets of the first identified theme of embodiment included (1) Aspects of a never-ending journey by being a donor (2) The scar and symbolic representations of the scar, like tattoos, became badges of honour and daily reminders of ongoing membership in transplant communities, (3) Transformative life experiences being living donors through birth, metaphor and reality, and self-creation, (4) Donor-derived benefits, (5) Embodied self-knowledge of living donation "feeling right" and (6) Embodied responses from family, friend and health care providers. In summary, embodying experiences of intuitively feeling right about donation were shared by participants in this study.

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Incorporated into the theme of ethical responsibility to one another were several facets contributing towards identification and understanding of the second theme of this study. All participants held strong personal beliefs about human interconnection and responsibility to one another as important values. Inquiring into participants' beliefs emerged through discussions of the meaning of the ongoing nature of being living liver donors. Participants willingly elaborated on features of spirituality, ethical responsibility and calls for action as integral components of being living liver donors.

Spontaneously initiating discussion of the concept and usage of the term "heroism" generated ambivalent responses in two participants. A1 spoke of her inability to respond when people spoke to heroism involved in anonymous donation, stating, "I don't think of myself as a hero. I just did what had to be done, and I did it because I thought it was right, and then people have this reaction and you don't know what to do". Being a hero created confusion and embarrassment for A1. In an email after the interview A1 wrote to clarify, both for A1 and the researcher, ambivalence about heroism. Finally understanding struggles with a significant individual and meaning of heroism through the interview process, A1 wrote,

(Individual) revelled in the hero worship and media attention. (Individual) did it (charity work). He wants and needs validation and gets it by using the body to out-do everyone. And then it hit me like a ton of lead; I had *outdone* (Individual). I had done the one thing (Individual) hadn't done; I had actually given up a piece of my body and I did it with no apparent benefit to myself...as a result of donation, this aha! moment brought me clarity and allowed me to make peace with it all.

Perceiving heroism as multifaceted, A2 explored numerous interpretations, disclosing competing qualities of selfishness and altruism as components of heroism:

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I don't feel like I did anything necessarily heroic...while I realize that it's a little more intricate than giving blood, to me it was kind of like, "Well, I go give blood to strangers," I mean people don't walk up to me and say, "You're a hero because you give blood," why would they say I'm a hero because I gave my liver? Mine wasn't a selfless act, and that's just it. For me, when people admire you for doing something it should be because you did something out of kindness or something, it wasn't a selfless act. I don't think this was a selfless act that deserves all this praise, I did something to help my (Recipient) and while I'm okay with people saying, "Oh, That's nice. That's great!" saying it's heroic, to me, it's just not right. Now the woman who donated anonymously, she talked to me about reasons for doing it, she has her own kids, she's older, she's like, "This is how I keep giving birth," and I remember thinking, "Oh that's beautiful."

All participants described facets of being part of something larger, belonging to the world and subsequently feeling a sense of responsibility towards one another. Describing commitment to values of interconnectivity with others, A1 began by saying,

I believe everybody has a responsibility to make the world a little better before they leave, and very few do now, very few people, and I think if we all took that to heart, the world would be a better place. Do what you can in your own little sphere of existence and look for the ripple effect to make other people say it's all right.

So I really believe we're all connected and what we put out there has an effect.

Weaving facets of interconnection and purpose for humankind, A4 endorsed a personal sense of purpose as an effort to please God, contributing to the identification of the theme of ethical responsibility to one another. A4 addressed the notion of humankind being interconnected

however asserting each person has a preordained purpose. A4 stated, “Yeah, we’re all tied together. And I do believe that God has a purpose for each person, but I also believe through my own life experience that we really don’t know what that purpose is. Maybe we will in the next lifetime.”

Evolving from unprompted discussions of interconnectivity during the interviews included another facet of the theme of ethical responsibility to one another; a call for action. Spontaneous appeals for policy changes related to living liver organ donation. All participants endorsed greater and more imaginative approaches for transplantation. Emphasizing individual acts drawn together can create enrichment for all; participants in this study were advocates for increased emphasis on promoting living organ donation. Describing positive experiences of donation led to deeper interconnection with humankind for participants. Embracing the role of being an ambassador for living liver donation, A1 stated,

Yeah, that’s part of why did it (donation), I thought two months out of my life makes a lifetime of difference for somebody else, and that’s ... I think that’s a pretty good deal. So, I mean, I’m not going to change any legislation by talking to one curious potential donor, or by helping you with the research, but it’s all baby steps, and it all starts adding up, and maybe it’ll get the ball rolling, and maybe somewhere down the road it’ll be easy for people to say, “Yeah, next year I plan to donate.” There are people out there who wake up every day not knowing if they are going to live or die, all for want of an organ. It’s heartbreaking and it’s avoidable.

Emphasizing a feeling of being fortunate to be a living liver donor, A4 also believed in moral obligation when appealing to others. Articulating belief in ethical responsibilities to move

the message beyond the operating room, A4 communicated desires for policy change by replying,

Well, just so I don't forget it I'll put a comment in here. Somewhere along the process, I felt like I have a bit of a mission. I'm not sure I really want to be much of a missionary, but I think this is a privileged thing that I've done. I'm very lucky. But I think in some ways it goes beyond the operating room, and perhaps communicating and raising awareness, you know, in the minds of other people, letting them know it's a good thing to do, to be part of helping save lives. God's given us two kidneys; one's a spare you know. Just like the gospel story where there's one person with two coats and another with none.

Discussing interest in increasing living donation awareness, A3 paralleled experiences between living liver donation and cancer survivors. Being stakeholders increased a personal sense of responsibility to create action, identifying another facet of the theme for ethical responsibility. Citing both group members affected by illness as stakeholders to enhance public awareness, and fully endorsing the donor experience, A3 commented,

I kind of feel the same thing with organ donation, it's the people who are...either their families have maybe received a donation, or they've donated, you know, someone's organs who have died, those are the people who can really push it. I wear a green ribbon, I have it on my winter coat. I like the idea I can be a small part of maybe making living donors more common. Like, if they came to us and said, "We need another transplant, and by the way we found a way that you can do it again," I absolutely wouldn't hesitate, I would go and do it again.

Supporting previous comments, A2 envisioned visible recognition for living liver donor

awareness campaigns. Creatively addressing revision of present donor campaigns, A2 imagined more effective images to increase organ donor awareness. Increasing awareness through effective advertising campaigns generated by donor stakeholders could affect donor rates and impact current policy regarding living liver donation. A2 asked,

Do you know what? I had this great idea for an advertising campaign to make people think about it (organ donation), because for me, that's my symbol of love. I thought if you see a commercial and it's like, "What's your symbol of love?" and someone's showing a diamond ring, and someone's showing a red rose, and someone's showing all these traditional things we see all these symbols of, like Valentine's Day and love, then someone's showing their scar.

Furthering discussion about commitment to expand public awareness of current living donor policy A1 is determined to personally lobby for policy changes. Discussing lack of parity between maternity leave and time away from work for organ donation and drawing parallels between these two events may have implications for living donation policy and recruitment in the future. A1 commented, "How come they do it for pregnant women and they won't do it for organ donors? How come people who want to... donate an organ can't get two months off work, never mind a year?"

Concluding, A2 reiterated and expanded on comments made by three other participants in this current study, saying,

I very much believe that what we do, we create our own destinies, we make decisions. No matter what happened to anybody, there are always points in our life where we get to decide who we want to be and who we are. This experience has profoundly helped me to define who I want to be and what I want the world to look like. I want

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the world to be a place where it wouldn't be considered heroic or massively selfless to give an organ. I want to live in a world where it would be ordinary and normal to do it.

Ethical responsibility to one another was a belief held by all participants and evolved as the second identified theme. Exploring the meaning of lived experiences of being living liver donors was the aim of this current study. Contributing insight into ethical responsibility to one another were several aspects revealed through discussions with participants. Incorporating these interrelated facets into the theme of ethical responsibility to one another increased understanding of the phenomenon of the lived experience of living liver donors.

Facets contributing to identification of the theme of ethical responsibility to one another included concepts of (1) "Hero," a term commonly used and endorsed by provincial donor advertising campaigns generated discomfort for participants, (2) Embodied spiritual interconnection with humankind becoming more apparent after living liver lobe donation, (3) Obligation to help one another as a universally held value, (4) Donor-derived benefits were perceived as both legitimate and serendipitous outcomes from transplantation and, (5) Living liver donors identified themselves as stakeholders actively endorsing creative changes to raise awareness, change policy and improve donor rates.

Summary

Introduced in Chapter 4 was interview data and analysis with summation of topics generated from participant interviews. Quotes from the participants revealed two themes: embodiment and an ethical responsibility to one another. Van Manen's phenomenological approach (1990) established a functional methodological structure for interchange between research activities. Exploring participants' concerns or what impeded or enhanced donation expanded current knowledge about living donation directly from participants' perspectives.

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Developing from this study was the emergence of two themes through the identification of the facets of each theme, embodiment of the living liver donors' experiences and an ethical responsibility to one another.

Fundamentally oriented in pedagogical tradition, van Manen believed this approach to be relevant and applicable to researchers in nursing, psychology, and for other professions attuned to a need for phenomenological awareness of lived experiences (van Manen, 1990).

Phenomenological inquiry, based on van Manen's approach regards research as a change agent.

Themes of embodiment and ethical responsibility to one another both increased knowledge

around embodied experiences of donation, current living donor decision-making and

development for potential policy changes within the transplant programs. The aim of Chapter 5

is to explore an interpretation of the meaning of data results through the use of poetics.

Expanding on the implications for current living donor policy includes a discussion of potential future changes in education, research, policy and practice.

CHAPTER 5: DISCUSSION AND IMPLICATIONS

A discussion of the results and exploration of personal reflections including an interpretation of embodied experiences of living liver donors through usage of poetics, is the focus in Chapter 5. Considering the significance of current living donor policy, recommendations and discussion of potential future opportunities for education, research, policy and practice included in this chapter. Examining local policy around assessment of living liver donors is also discussed.

Interpretation of data results in Chapter 5 occurred through previously described methodological steps including reviewing memos after the interview, reading transcripts as a whole, highlighting key words or phrases, and line-by-line analysis of transcriptions. Through imaginative reflection on responses gathered from the interview questions with study participants, two themes emerged related to the phenomenon of the experience of living liver donation. In Chapter 5, exploring the themes that arose from the interview questions are discussed.

Interpretation of Data Results

Theme One: Embodiment and the Experience of Being a Living Liver Donor

Throughout transplant literature, concepts of embodiment, altruism and a change in quality of life for the donor have been partially addressed; however, solely from a quantitative perspective. Information generated from the studies has not explored donor-generated perceptions of the lived experience (Beavers et al., 2001; Bronner et al., 2002; Crowley- Matoka et al., 2004; DuBay et al., 2010; Erim et al., 2006, 2007; Fisher et al., 2005; Kroencke et al., 2006; Lennerling et al., 2003; Trotter et al., 2007). This new knowledge, generated from donors'

descriptions of a never ending journey through transformative, embodied experiences will increase understanding of the donor's experience.

This current study adds to the current literature in that the participants all spoke to the transformative, donor-derived benefits as facets of embodiment in being a living liver donor. Previously, observations from participants' information had not been expanded upon in quantitative studies. Implications for this exploration into the transformative nature of the experience could be further explored through additional research in this area. Considering embodied experiences of donors as valid reasons to donate, Shanteau et al., (1992) concluded donor-derived benefits were acceptable and important factors to consider in evaluation processes. Justifying donor-derived benefits and not solely focusing on the recipient through experiences of transformation could have positive implications for donation rates in Ontario.

Identifying embodied experiences of donation were of central and significant interest for participants in this study of living liver donors. Defining embodiment means "to put into a body, give body to, incorporate or offer tangible, bodily, or concrete form to self, object, or another person" (Oxford Dictionary of Etymology, 1966, p. 308). Embodiment, in the context of describing and interpreting experiences and the meaning of liver lobe donation, includes the concept of aesthetic proprioception.

Defining the following term offered both an explanation of the meaning of embodiment and a poetic understanding of proprioception. Olson (1974) incorporated perceptions of one's own body with reference both to individual experiences of proprioception as well as a shared, universal understanding of the phenomenon. Olson suggested a sense of intuited knowledge within the body, stating proprioception is:

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Physiology; the surface (senses- the 'skin': of 'Human Universe') the body itself- proper- one's own 'corpus': PROPRIOCEPTION the cavity of the body, in which the organs are slung; the viscera, or interoceptive, the old 'psychology' of feeling, the heart; of desire, the liver; of sympathy, the 'bowels'; of courage-kidney etc-gall (Olson, 1974, p. 17).

Describing aesthetic knowledge of proprioception included not simply neurological understanding, but also, "data of depth sensibility, the 'body of us' as object which spontaneously produces experience 'with depth'" (Olson, 1974, p. 17).

Affirming the soul as central, proprioceptive, and integral to a sense of self and identity, aesthetic proprioception included awareness of a specific place in the unconscious. Olson, a poet and philosopher, described souls as "proprioceptive, the universe is one and the self is the universe flowing in, inside" (Olson 1974, p. 19). Speaking to a sense of wordless knowledge described by participants in this study; this esoteric description captured essences of participants' embodied donation experiences.

Participants used embodied and proprioceptive metaphors of the body. Scarring, the meaning of the surgical scar, and tattoos represented identification with and endorsement of the living liver donor experience. All participants in this study used creative metaphors about the journey of life, including the powerful and life altering experience of offering life to another. Likening this experience to giving birth, a participant drew analogous comparisons between legalized parental leaves from work and the need for policy changes for living donors. Birth and creation metaphors, used by all participants, added further richness to descriptions of embodiment through living donation. Participants uniformly described the experience as a deepening inter-connective experience with the recipient and extending this embodied experience to include the world.

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Van Manen encouraged artistic forms as textural sources and as a means of expression (1990). Sensitively attuning to unique experiences' embodiment in living liver donation, poetry allows interpretation of intense and at times inexpressible feelings. Poetry can transform and interpret ordinary human experience in infinite variety. Poetic language can authentically speak to the world rather than speaking *of* it. This poetic interpretation is language reverberating throughout experiences of the world (van Manen, 1990). Accepting concepts of interconnectivity between donor, recipient and world as well as interaction between participant and interviewer, Creeley's poem *The Plan is the Body* (1982) perfectly illustrates themes of embodiment as described by participants in this study. Incorporating principles of aesthetic and intuited proprioception, as defined by Olson (1974), the poem expresses interconnection within the self and humankind, the immediacy of embodied knowledge and trust in inner wisdom.

The Plan is the Body

The plan is the body.
There is each moment a pattern.
There is each time something
for everyone.

The plan is the body.
The mind is in the head.
It's a moment in time,
an instant, second.

The rhythm of one,
and one, and one, and one.
The two, the three.
The plan is *in* the body.

Hold it an instant,
in the mind- hold it.
What was said you
said. The two, the three,

times in the body,
hands, feet, you remember-
I, I remember, I-
speak it, speak it.

The plan is the body.
Times you didn't want to,
times you can't think
you want to, *you*.

Me, *me*, remember, me,
here, me wants to, *me*
am thinking of *you*.
The plan is the body.

The plan is the body.

The sky is the sky.

The mother, the father-

the plan is the body.

Who can read it.

Plan is the body. The mind

is the plan . I-

speaking. The memory

gathers like memory, plan,

I thought to remember,

thinking again, thinking.

The mind is the plan of the mind.

The plan is the body.

The plan is the body.

The plan is the body.

The plan is the body.

Robert Creeley (1982, p.166)

Delineating three key principles of Creeley's work, Bernstein discussed "The Plan Is the Body." Discovering what has to be said in the process of saying it, poetry is made not of ideas but of words; poetry should emphasize equally the common and the particular, or rather seek to find the particular within the common (Bernstein, 2006). Embedded in this poem is wordless

knowing within the body, the iterative nature of pre-cognitive understanding. Overlapping themes shared by donors include interconnection with self, other, and the world.

Van Manen asserted that phenomenology is both a description of the lived experience and a portrayal of the meaning of the lived experience (1990). Further commenting on this statement, van Manen (1990) underscored the interpretation of meaning as a mediated expression of thought and is therefore interpretable, stating,

Objects of art are visual, tactile, auditory, kinetic texts-texts consisting of not a verbal language but a language nevertheless, and a language with its own grammar. Because artists are involved in giving shape to their lived experience, the products of art are, in a sense, lived experiences transformed into transcended configurations. (p.74)

Poetry is an activity, a device to put words to both articulated thoughts and to give voice to the repetitive, unspoken and often shared experience of embodiment understood by living liver donors in this study.

Evidenced-based nursing knowledge is the standard used to measure nursing knowledge in Ontario; it can be learned, taught, evaluated and constantly changes. The purpose of this current study was to explore the unknown and ask, from the participants' perspectives, what is of interest to them, as living liver donors. The use of poetry in the analysis permitted an interpretable understanding of the embodied experiences for everyone, not only live donors. Using poetry to express a limbic recognition of truth has implications for nurses considering hermeneutic, phenomenological studies. Recently, body-mapping, asking participants to draw their perceptions of their own bodies after transplant, revealed graphic inter-connective images of themselves linked with their deceased donors (Rivest et al., 2010). There is freedom in and

through interpretation and exploration of many phenomena of interest through interpretation of the expressive meaning in art.

In a current radio documentary about the architect, artist, poet, writer and political activist Ai Weiwei, unlawfully detained in China, talked about the power of art saying, “Art is supposed to be about life because art is life. Because my, your, our life is political, every single art piece is political” (Weiwei, 2011). In a similar way, and expanding on the poetic interpretive understanding of this phenomenological study, nurses can explore the value of various art media to express new ways of conducting research. Drawing attention of nursing concerns to the public may include expression of artistic interpretations in nursing areas of interest to students.

Theme Two: Ethical Responsibility to One Another

Emerging repeatedly in interviews with all participants was commitment to ethical responsibility for the generation of change and saving lives through living liver donation. Reviewing the present literature on the initiation of ethical responsibility, post living donation did not yield results; living liver donors’ sense of ethical responsibility to one another is a new area of interest to be further explored. Each participant deliberately requested that participation in this study generate increased interest and understanding of living liver donation.

Meeting impediments to living liver donation was a collective facet in the theme of ethical responsibility and was shared by all participants. Participants in this study described meeting some resistance from family members, doubt from friends as well as disapproval from members of the transplant health care team and other health care professionals. Demonstrating a lack of awareness, personal bias, and possible medical paternalism in knowing what is best for the patient highlighted the need for public awareness campaigns and donor assessment policy changes.

Implications: Education

Van Manen believed phenomenology is a critically oriented action research approach (1990). Fundamentally oriented in pedagogical tradition, van Manen considered this approach to be relevant and applicable to nursing researchers attuned to the need for phenomenological awareness of lived experiences (van Manen, 1990). As a critically oriented action research approach, phenomenological research can be a catalyst and change agent.

A goal for education, arising from this study, is to incorporate the results into the nursing curriculum. Nursing is both an art and science. The encouragement of various forms of artistic interpretations to express living liver donor experiences into the present nursing curriculum could tap creative resources in nursing students. Using art as a means to understand the experiences could establish increased appreciation and further understanding of this phenomenon.

Identifying themes of embodiment and ethical responsibility to one another may lead to learning about other thematic aspects of the lived experiences of the living liver donors. This suggests opportunities, previously untapped, to include living liver donors as strong advocates for Trillium Gift of Life Network. Considering embodied experiences of donors as valid reasons to donate, Shanteau et al., (1992) concluded donor-derived benefits were acceptable and important factors to consider in evaluation processes. Supporting this claim, Trillium could learn from donor experiences to educate the public and raise awareness of transplant shortage and ways to increase living donation.

Previously lacking evidence-based data to objectively sort through inherent differences of meeting the competing needs of donor and recipient, Surman et al. explored ethical conflict by turning to kidney donor literature (2005). A highly motivated donor who stood to benefit from

the surgery made ethical tensions less ambiguous. Including and disseminating new knowledge through schools and healthcare provider curricula could alter preconceived ideas about living liver donors. Similar to a paradigmatic shift in pain management from standardized delivery of pain medication to include the patient's own perceptions of pain, living donors could describe the experiences of living donation and increase knowledge about this comparatively new procedure.

Non-cognitive, visceral, irrational factors often drive health-related decisions for donation (Morgan, Stephenson, Harrison, Afifi, & Long, 2008). Variables in this quantitative study included knowledge, attitude, social norms, and behavioural intentions. By extension, results from this current study, identified by participants, were similar and at times negative responses from family, friends and members of the health care team. Countering these observations, Morgan et al. (2008) insisted donor decisions, though not based on linear, rational thought processes, must be respected when promoting organ donation.

Participants in this study universally identified gaps in knowledge to enhance living liver donor awareness and felt the need to follow ethical responsibilities to publicize living liver donation. Understanding then incorporating both cognitive and non-cognitive factors could positively influence the outcome for increased organ donation (Morgan et al., 2008). Reinterpretation of living liver donors' personal, described experiences may affect currently held perceptions for members of the public as well as health care professionals. Exploring health care team members' perceptions of living donation alongside those of the donors may suggest new approaches in clinical practice. Donors can initiate increased understanding of embodied donor experiences through education, and towards advocacy for evocation of changes in living donor policy.

Implications: Research

Expanding on poetic interpretation of embodiment in this study, nurses can explore various art media to conduct further research. Supporting this claim, “body-mapping” (originally used to understand the lived experiences of people with HIV/AIDS but now implemented with liver recipients) revealed graphic inter-connective images of liver transplant recipients linked with their deceased donors (Rivest et al., 2010). There is freedom in and through interpretation and exploration of many phenomena of interest through interpretation of the expressive meaning in art.

Fox and Swazey (1992) spent more than 40 years observing transplant centres, and believed transplant surgeons and psychiatrists went to extreme lengths to uncover emotional conflicts and ambivalence with potential donor’s decision to donate a kidney (1992). No single method for donor assessment criteria exists between centres. Turning away potential living donors, if motivation was deemed inadequate, became the safe stance for many transplant programs (Fox & Swazey, 1992). Countering identification of psychopathology as opposed to understanding potential donor’s interest in living donation suggests another thematic facet to explore through phenomenological research.

Furthering research with living liver donation experiences could be the exploration of other thematic facets identified in this study, particularly health care professionals’ responses to anonymous and directed donation. Bryant (2008) described obstacles she met during the donor pre-transplant assessment process. Recalling suspicion and obstruction encountered with transplant teams, Bryant was frustrated by attempts to become an anonymous living donor.

Surman et al. (2005) supported an alternative ethical option, encouraging colleagues to

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view the donor as a surgical patient for whom the operation is merely that- a procedure with the usual attendant risks and benefits. This reliance on medical paternalism opposed the viewpoint of donor autonomy and did not address the lived experience of embodiment in living liver donation. Suggesting the adoption of anonymous or directed living liver donation, Bryant concluded efforts could close the gap between the need and ability to provide usable organs (2008). Conducting further research will provide opportunities to understand what factors contribute to the decision-making person process.

Psychological benefits for living liver donors were intangible and difficult to establish. Reported advantages of subjective donor-derived benefits strengthened ethical justification for living anonymous donation (Wright, Ross, Abbey & Levy, 2007). Recounting psychological benefits included tangible expressions of altruism, motivation, and the act of donation consistent with spiritual beliefs (Wright, Ross, Abbey & Levy, 2007). A hermeneutic, phenomenological study using van Manen's methodological approach could increase understanding into the meaning of donor-derived benefits for living liver donors.

Implications: Policy

The role of policy is to put in place processes to support interest in living liver donation. Van Manen believed phenomenology is a critically oriented action research approach, using research as a change agent (1990). Incorporating results from this current study includes the possibility for research for change in the presently held living donor policy. Related to local organ donor policy levels, recommendations to the Trillium Gift of Life foundation are the creation of official platforms and symposia for donors to speak about experiences with living liver donation. Creating policy to include donors in campaigns would enhance knowledge and send powerful messages to increase live donation awareness. Participants in this study felt

personal enrichment through living liver donation.

One study from the literature search reviewed comparisons between living kidney and liver donors. Rudow, Charlton, Sanchez, Chang et al.(2005) commented it was an easier decision and process for living kidney donors. Describing a greater chance of death, bleeding and complications for liver donors made the decision to donate more challenging. There is always an option for dialysis for patients with end-stage renal failure. In this current study, participants endorsed living liver donation as especially meaningful because the sole outcome for patients in end-stage liver failure is death. Living liver donors in this study acknowledged the uniqueness of their position, endorsing it as a never-ending journey and ascribing life-giving meaning to the act of donation. Acknowledging present gaps in living kidney and liver donor literature, participants in this phenomenological study perceived themselves as ambassadors for living liver donation.

Living liver donors should be celebrated and acknowledged for participating in this revolutionary approach to saving lives. To be labelled as “heroes” created ambivalent feelings for participants in this study. Establishing donor-derived benefits as an acceptable rationale to donate while questioning safe fallback to medical paternalism could impact donation rates. While not all potential donors are suitable from varying clinical perspectives, nursing research to further explore what impedes or enhances donor experiences might influence living liver donor policy on a provincial level. Furthering an exploration of the complexity of feeling surrounding the meaning of *hero* through research might suggest new ways to honour and support living donors.

Traditionally, turning away potential living donors, if motivation was deemed inadequate, became the safe stance for many transplant programs (Fox & Swazey, 1992). Emphasis on the presence of psychopathology over genuine interest in being a living donor was partially

circumvented with adherence to rigorous psychosocial assessment and safeguards for potential donors (MacFarquar, 2009). Rationalizing the need for rigorous assessment as a precautionary measure became acceptable practice. Transplant health care professionals acknowledged these precautions would no longer be needed once living donations became an increasingly accepted procedure. Benefiting from a universally accepted psychosocial process could engage the potential donor about the meaning of stepping forward to volunteer. Advocating for a new approach in the assessment process, creating space for genuine inquiry into the experiences of donors could alleviate individual health care team professionals from the responsibility of subjective decision-making about who may become a living liver donor.

To summarize, considering the complexity of ethical issues generated by live donor transplants, a surgical procedure that is just 20 years old and places healthy individuals under physical, psychological, and financial stress, with no known long-term outcomes generates caution. The current trend in assessing donor candidates emphasizes the absence of psychopathology rather than discursive engagement about desire to donate. This medically generated rebus could be addressed through qualitative nursing research and implementation of change. Psychosocial interviews guided by skilled psychosocial nurses could decrease subjective bias and support fully informed voluntary use of donor candidates.

Implications: Practice

Acknowledging the complexity of ethical issues generated by the desire to donate a liver lobe has been previously described. A recommendation for future practice would include the establishment of a group of health care professionals drawn from multiple health care centres to evaluate current assessment practices of living liver donors. Psychosocial nurses can contribute

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much to this process through identification of potential donor's desires to move forward while balancing concerns of potential coercion, understanding informed consent and consideration of the potential donor's mental health history. Improvement of pre and post donor experiences while ensuring safe clinical practice is a goal and a shared team responsibility.

An increased understanding of the embodied donor experience can lead to advocacy and evocation of change. An additional aspect of the donor experience to consider is the inclusion of participatory action research with living liver donors as stakeholders and members. Participatory action research involves people actively becoming engaged with an issue, seeing the involvement as a continuous process of reflection that is ultimately transformative. Participants in this study all perceived themselves as stakeholders for the promotion of living liver donation.

The inclusion of living liver donors' voices would influence health care professionals who need to learn more about the life- altering, embodied experiences that donation may offer. Informed donor decisions, supported by further research and education in this area may enhance pre and post donor experiences. Living liver donors' ethical responsibility to one another asks for opportunities to enrich awareness and could positively impact living donation rates.

Limitations of the Study

Scope and Limitations

No approach is flawless; using qualitative hermeneutic phenomenological inquiry to understand donor experiences is not without pitfalls. Bias, insistence, or emphasis on certain interpretations of embodiment can inadvertently misrepresent what participants intended. Any particular analysis is often more complex than can be conveyed (van Manen, 1998). In perceiving power imbalances, bias can often exist in phenomenological studies through interactions with participants. Emphasis on certain aspects of the interview questions while diminishing focus on

other areas deemed important by participants may lead to imprecise interpretation of participant experiences. Insisting on a reflexive and strong relationship between researcher and participant and one that is responsive to changes in subject matter is integral to any study (van Manen, 1990). Interviewing participants could generate different interpretations due to varying degrees of ease with interviewers, sense of rapport, mood, time of day, and setting.

Using a phenomenological approach, van Manen advised awareness of constant measurement, understanding, and insight against the lived reality of our concrete experiences (1990). Attuning to participants who brought their own world view into each conversation required continual adjustment from this researcher to engage honestly in conversation. Pursuing understanding through use of this philosophical framework did not presuppose fundamental assumptions of a human science perspective (van Manen, 1990). A sample size of four participants at a single transplant centre limited the impact of the study.

The personal nature of topics related to embodiment, altruism, and self had the potential to create measures of distress for some people. Informing participants of personal rights to decline responding to any questions addressed this concern. Assuring participants a colleague in the psychosocial department would be available to debrief if participants chose provided additional support. Considerable reporting in the literature indicated participants found unstructured interviews validating and offered opportunities for introspection and growth (Frank, 2000; Honeycutt, 1995; Hutchison et al., 1994; Morse, 2003; Ortiz, 2001). Although there is evidence qualitative interviews may cause psychological distress, there was no indication emotional risk was any greater during the interviews than in everyday life experiences (Morse, 2003).

Personal Interpretation and Reflection

Working since the inception of the living liver donor program, this researcher is the medical psychiatry clinical coordinator within the Multi-Organ Transplant Program. Assessing candidates for psychosocial suitability to donate a liver lobe led to interest in exploring what donors felt about living donation experiences. In the clinical setting prior to this study, post transplant donors often stopped by this researcher's office at their scheduled six-month post donation appointments. Casually mentioning shifting sleep patterns, heightened emotionality, and changes in satisfaction with life, these men and women spontaneously articulated disquieting senses of personal transformation, initiated by the donation experience.

These feelings were not easily understood or conveyed. While no person has yet articulated regret over decisions to donate, those who spoke of donor experiences often shared similar perspectives. Wondering if the donated liver lobe was well received and cared for, anonymous donors often expressed curiosity about recipients, for example, musing if the recipient was alive and enjoying life. Emotional shifts from the act of sharing a liver lobe and feeling interconnection with liver recipients infused new meaning into life for donors. Sharing conflicting emotions, donors spoke in existential terms about ethical considerations for one another and the purpose of life.

Creating impetus for this current study was curiosity about living organ donors' experiences. Describing life-altering events in a clinical setting, several patients radically changed careers, relationships, and living situations. Many conversations centred on themes of faith and spirituality; in essence, loss of faith or reengagement with spirituality on their own terms. Surprised by the emotional impact generated by the act of donation, the transplant team attempted to quantify patients' quality of life in an effort to understand unanticipated emotional

responses. Understanding the lived experienced described by participants post donation was the focus of this current study.

What living liver donors truly experienced, why they felt compelled to donate was of considerable interest for this researcher. In the clinical setting, there was often a sense perspective donors would say what was expected to get through the interview process in order to donate a liver lobe. Discussing life-altering events with donors after transplant convinced this researcher the experience potentially had enormous impact. There was a need to explore what post living liver donors were experiencing, in their own words. Nothing prepared this researcher for the extraordinary insights, frankness, and commitment offered by the participants in this study. All participants felt a sense of interconnection, responsibility, and belonging to the world. These insights led to strongly held beliefs in donor-derived benefits and transmission of this message to advocate for increased living liver donor awareness.

Van Manen (1990) advised phenomenological studies and methods often have a transformative effect on the researcher as well as the participant. Being a part of this current study was an extraordinarily moving process for this researcher, creating feelings of interconnection between donor and recipient, donor and researcher, donor and the world. Freed from time constraints in the clinical setting, and an agenda to retrieve answers to predetermined questions about motivation to donate, this researcher re-experienced an embodied connection to the participant, separate from the constrictions of time. Van Manen asserted the goal of phenomenological understanding is to gain knowledge and translate that knowledge into action (1990). This researcher remembered what it was like to spend time with patients and truly listen without having to get something from the exchange. Respecting the request by two participants to disseminate the findings of this study and to promote living donation, this researcher felt

renewed by their commitment to saving lives and will continue to be involved in living donor promotion and awareness.

Reflections on this Study

Embodiment, as experienced by living liver donors, has not to date been described in transplant literature. Quantitative studies reviewed in the literature search for this current study did not fully address the phenomenon of embodied living liver donor experiences. Interview questions were predetermined and often measured with scales or solely binary options for response. Encountering moments of suffering, identified by distressed patients in post-donor clinics led this researcher to question the emotional conflict evoked in donors by the experience of becoming living liver donors. Offering limited psychosocial assistance in post transplant clinics was not helpful as only visibly distressed donors were identified as needing support. Through opportunities to talk, donors described powerful transformative experiences stemming from living donation. Some donors radically changed life paths, including partners, careers, and vocation.

Conclusion

The purpose of this current study was to explore the meaning of the lived experiences of living liver donors. Creating possibilities of increased awareness provided an opportunity to gain nursing knowledge and translate this knowledge into action for further nursing research, education, practice and changes in local policy for living liver donors. Arising from this current study, two themes emerged from participant interviews. These themes are (1) Embodiment in the experience of being a living liver donor and (2) Ethical responsibility to one another. Focusing on ethical responsibilities to generate changes through increased organ donor awareness, personal empowerment and questioning the status quo can result in increased awareness of living

donor issues. New perspectives for nurses delivering information to potential donors can advocate for provincial policy changes. These potential changes may include a reworking of a thorough psychosocial assessment interview, engaging potential donor candidates in discursive understanding about the wish to donate.

Appreciating embodiment through the lived experiences of living liver donors determined the purpose of this qualitative, phenomenological study. Garnering insight into the phenomenon of embodied living liver donor experiences has not been previously described in transplant literature.

Four living liver donors participated in this qualitative, hermeneutic phenomenological study. Taping interviews and reading transcriptions line-by-line as outlined in van Manen's (1990) methodological approach revealed subsequent thematic concerns. Emerging from the interviews and application of van Manen's methodological approach towards understanding this phenomenon arose two themes. These themes are: (1) The embodied experience of being a living liver donor and (2) Ethical responsibility to one another and to the world.

Phenomenological inquiry is unlike other forms of research, in that phenomenology cannot create definitive statements or final summation (van Manen, 1990). Commenting on the relationship between phenomenology and poetry, van Manen (1990) spoke of futility for both in "listening in vain for the punch-line" (1990, p. 27). As in poetry, asking for a summing up of a phenomenological study is unlikely. To summarize a poem would spoil the result because the poem itself is the result (van Manen, 1990). Participants in this study embodied a sense of living donation as a never-ending journey, describing interconnection to self and the world and commitment to enhance awareness about living liver donation. Speaking to difficulties articulating such profound experiences, van Manen (1990) offered,

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What we must do is discover what lies at the ontological core of our being. So that *in* the words, or perhaps better, *in spite of* the words, we find memories that paradoxically we never thought or felt before. (p. 27)

Accompanying this researcher through participants' explorations of embodiment of lived experience of living liver donors, Robert Creeley's words (1982) resonated throughout this journey:

The plan is the body.

There is each moment a pattern.

There is each time something

for everyone.

Appendix A: Introductory Letter

Title: The Experience of Living Liver Donors

Investigator: Sarah Greenwood RN, BScN, CPMHNC

Dear Living Liver Donor,

My name is Sarah Greenwood and I am a Registered Nurse at the University Health Network. I am the Transplant Psychosocial Nursing Coordinator for the Living Liver Donor Program and I am studying for a Master of Nursing degree at Ryerson University. I have chosen to study what it is like to be a living liver donor and would be interested to hear about your experience of having donated a liver lobe to another person.

The purpose of this research study is to explore and establish a deeper understanding of what it means to you to be a living organ donor. Because little has been written or is known about the lived experiences and complexities involved in living liver donation, it is important to ask you, the person, about your experiences in order to expand our knowledge of this phenomenon. Your

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story is unique, and your voice and your story is what are valued and most important to me and that is why you are being approached.

I would like to interview three to five people for this study. If you decide you would like to hear more about the study, or participate in the study, please give your verbal consent to the team member who approached you with this information and I will contact you by telephone to provide more details. Thank you for considering this request to participate in this study.

Sincerely,

Sarah Greenwood RN, BScN, CPMHNC (Master of Nursing student) Ryerson University

Appendix B: Consent to Participate in a Research Study

Title: The Experience of Living Liver Donors

Investigator: Sarah Greenwood RN, BScN, CPMHNC

24- Hour Phone Number: N/A

Sponsor: N/A

Introduction:

Before agreeing to participate in this study, it is important you read and understand the following explanation of the proposed study procedures. The following information describes the purpose, procedures, benefits, discomforts, risks and precautions associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. A refusal or withdrawal from the study will not affect your care in any way. In order to decide whether you wish to participate in this study, you should understand enough about the risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the study nurse to explain any words you don't understand before signing the consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

Title: The Experience of Living Liver Donors

Investigator: Sarah Greenwood RN, BScN, CPMHNC

Rights as a Volunteer

Participation is voluntary and it is your right to decide whether you choose to participate, to refuse to participate or withdraw from the study at any time. A refusal or withdrawal from the study will not affect your care in any way and you have the right to withdraw without any penalty and implications for any treatment or care you receive.

Background and Purpose of the Study

The gap between the increasing demand for transplantable organs and the supply of organs has been widening exponentially in the past years. As a living liver organ donor, you have already demonstrated a commitment to your belief in the need for organ donation by offering to come forward for surgery.

The purpose of the study is to ask what it is like to be a living liver lobe donor. Your unique experience can perhaps shed some light on why some people step forward and become donors. Presently, there is very little written about the complex motivations to volunteer for this surgery. You will be asked to come in for one interview with the investigator; this interview will take approximately one hour of your time and you will choose the best time for you to come. Approximately three to five people who have donated a liver lobe at The University Health Network, Toronto General Hospital will be participants in this study. Little is known at the present time about the meaning of being a living donor. If we can learn from you a bit more about your hesitations and hopes, what impedes or motivates donation, our knowledge in this area will expand and we may begin to understand more about what it is really like to be a living liver donor, most importantly with your input.

Procedures

You have already been approached by a member of the living liver donor team to ask if you would be interested in participating in this study and after reading an information letter, have

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agreed to let the investigator call you to offer further information and potentially be enrolled in the study. You will be able to choose a convenient time for the interview that will take approximately forty-five minutes to one hour of your time. This is a qualitative research study, using purposive sampling of living liver transplant donors, conducted by a Master of Nursing candidate for her thesis. This means the study is aimed at understanding what it is like to be a living liver donor and draws participants from this specific population. The investigator will review the focus of the study, respond to any potential questions and witness your signing of the consent form.

You will be interviewed in a private office and the conversation will be audio taped. The interview will start with an open-ended question and may include other open-ended questions around your experience of being a donor, if the discussion opens up new thoughts for you. The interview may be brief but may be as long as forty- five to sixty minutes.

Eligibility

All potential participants may be male or female adults over the age of eighteen and must be able to speak English. They have all experienced the phenomenon of being living liver donors, and have been interviewed previously about their suitability to donate and have undergone surgery to donate a liver lobe to a recipient.

Risks and Inconveniences

There are no medical risks if you take part in this study but being in this study may make you feel uncomfortable as we talk, and as you describe your thoughts and feelings about what it was like for you to be a donor. It is possible to feel some emotions and some may be quite strong: anxiety, stress, embarrassment or even feelings of sadness. There will be time to pause, you may decline to answer the question, or you may choose to end the interview at any time. Additional support from a colleague on the psychosocial transplant team will be offered and made available should you choose.

Benefits

While there may be no direct benefit to you as we move through the interview, this opportunity may offer a chance to reflect on your experiences about the donor process and to discuss your thoughts with another person. The information you provide and stories you may share will benefit others and certainly contribute valuable information on what little is already known about the experiences of living liver donors.

Voluntary Participation

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and later decide to withdraw. You may leave the study at any time without your decision affecting your care. You may refuse to answer any question you do not want to answer, or not answer an interview question by choosing to pass on the opportunity to respond.

Confidentiality

Personal Health Information:

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If you agree to participate in this study, the study nurse and the co-investigators will look at your personal health information and collect only the information they need for the study. Personal health information is any information that could be used to identify you and includes your:

- name
- address
- date of birth

The information collected for the study will be kept by the investigator in a locked, secure area for twenty-five years. Only the people or group listed below will be allowed to look at your records. If you decide you would like to participate, your name will be entered in to a screening log and you will be assigned a unique identification number in to preserve confidentiality. Your participation in this study will also be recorded in your medical record (OTTR) at this hospital. The following people may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct, and to make sure the study followed proper laws and guidelines:

- Representatives of the University Health Network Research Ethics Board.

Compensation

You will be given a gift certificate for Tim Horton's for \$10.00 for your time and your offer to share information about your experience being a living liver lobe donor.

Questions

If you have any questions regarding this study prior to your consent, please call the investigator, Sarah Greenwood R.N. at 416- 340- 3962.

If you have questions about your rights as a research participant, or have concerns about this study, please contact Dr. Ron Heslegrave, Ph.D, Chair of the Research Ethics Board at the University Health Network, 416- 340- 4557 to discuss your concerns. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

CONSENT

This study has been explained to me and any questions I had have been answered.

I know my participation is voluntary and I may leave the study at any time. I agree to take part in this study.

Print Study Participant's Name

Signature

Date

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions pertaining to the volunteer rights, purpose, procedure, design, potential risks and benefits and compensation and consent for this study.

Print Name of Person Obtaining Consent

Signature

Date

Appendix C: Interview Questions

Overarching Question:

- 1) What is it like to be a living liver donor?

Potential sub-questions:

- 2) What types of factors may have contributed to the decision to donate a liver lobe?
- 3) If you are comfortable, please tell me a bit about your personal beliefs around the meaning of your life.

Appendix D: Budget

Salaries	Tasks	Time	Rate	Cost	Notes
Investigator	Proposal development and approval Ethics approval Consenting the study participants Collecting Data Analysis of data Dissemination of findings	January 2009-May 2010	Nil	Nil	
Consultants					
Transcriptionist	Purchase Service	12-20 hours	\$25.00 per hour	\$300.00-\$500.00	Three to five interviews x one hour x 4 hours of transcription
Non-Personnel					
Participant Token thank you gift.	Tim Horton's gift certificate		\$10.00	\$30.00-\$50.00	
Total Study Cost				\$330.00-\$550.00	

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