



## Grief and loss for patients before and after heart transplant



Jennifer Poole, MSW, PhD<sup>a,\*</sup>, Jennifer Ward, BSW<sup>a</sup>, Enza DeLuca, MN<sup>b</sup>,  
Margrit Shildrick, PhD<sup>c</sup>, Susan Abbey, MD<sup>d</sup>, Oliver Mauthner, MN, PhD<sup>e</sup>,  
Heather Ross, MD<sup>b</sup>

<sup>a</sup> School of Social Work, Faculty of Community Services, Ryerson University, 350 Victoria Street, Toronto, Ontario M5B 2K3, Canada

<sup>b</sup> Division of Cardiology and Transplant, University Health Network, 585 University Avenue, PMB 11-137, Toronto, Ontario M5G 2N2, Canada

<sup>c</sup> Tema Genus, Linköping University, Linköping 58183, Sweden

<sup>d</sup> Department of Psychiatry, University Health Network, 585 University Avenue, PMB 11-100D, Toronto, Ontario M5G 2N2, Canada

<sup>e</sup> Institute of Nursing Science, Faculty of Medicine, University of Basel, Bernoullistrasse 28, 4056 Basel, Switzerland

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### ABSTRACT

**Objectives:** The purpose of the study was to examine the loss and grief experiences of patients waiting for and living with new hearts.

**Background:** There is much scholarship on loss and grief. Less attention has been paid to these issues in clinical transplantation, and even less on the patient experience.

**Methods:** Part of a qualitative inquiry oriented to the work of Merleau-Ponty, a secondary analysis was carried out on audiovisual data from interviews with thirty participants.

**Results:** Patients experience loss and three forms of grief. Pre-transplant patients waiting for transplant experience loss and anticipatory grief related to their own death and the future death of their donor. Transplanted patients experience long-lasting complicated grief with respect to the donor and disenfranchised grief which may not be sanctioned.

**Conclusions:** Loss as well as anticipatory, complicated and disenfranchised grief may have been inadvertently disregarded or downplayed. More research and attention is needed.

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### Introduction

Heart transplantation is the accepted therapy for patients with advanced heart failure. Many return to 'normal' lives, but many face challenges such as rejection, infection, renal dysfunction, and cancer. Some may also experience depression, anxiety and others types of distress.<sup>1</sup> Previous findings made clear that 88% of heart transplant recipients' (HTR) interviewed expressed feelings of distress,<sup>1</sup> and all patients listed for heart transplant expressed feelings of loss.<sup>2</sup> To explore these issues further, a secondary qualitative analysis of existing audio and visual interview data was conducted. The purpose of this article is to outline the subsequent findings of that analysis with respect to the loss and grief experienced by patients before and after heart transplant.

### Grief

Outside clinical transplantation, much has been written on loss and grief.<sup>3–16</sup> Attempts to understand grief reactions and the differences between 'normal' and 'problematic' forms of grief have been underway for over a century,<sup>5</sup> as have critiques of the application of linear, step-based models of grief.<sup>4,5,7,17</sup> Although the widely adopted stage model of grief was introduced by Elisabeth Kubler-Ross in 1969, she argues it was only intended as a guide, for grief is "not just a series of events, stages or timelines" and cannot be contained conceptually.<sup>18</sup> Nevertheless, conceptual models or frameworks abound,<sup>7</sup> and scholars continue to expand on grief categories, typologies and tasks.<sup>3,9,11–13,16,19,20</sup>

In addition, several other themes remain constant through much of the broader grief literature. Some contend that each experience is as unique as the person who grieves and the relationship they had with the deceased.<sup>3–5,7,9,14,16,20</sup> Arguments have been made that bereaved individuals 'continue bonds' with the deceased after death.<sup>4,5,16,17</sup> Others focus on 'making meaning' of the death<sup>7,11</sup> or 'appreciation of transformation.'<sup>3</sup> Finally, developments in the 'new science of bereavement'<sup>4</sup> have identified that resilience is another central notion in understanding loss and

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\* Corresponding author. School of Social Work, Faculty of Community Services, Ryerson University, 350 Victoria Street, EPH-220, Toronto, Ontario M5B 2K3, Canada. Tel.: +1 416 979 5000x6253; fax: +1 416 979 5214.

E-mail address: [jpoole@ryerson.ca](mailto:jpoole@ryerson.ca) (J. Poole).

grief, and one which has also been used to differentiate between 'normal' and severe grief reactions.

### *Grief and organ donation*

When it comes to the clinical literature on grief and organ donation, the research has been more concerned with donor families and not patients before and after transplant.<sup>21–23</sup> This donor family scholarship speaks to both positive<sup>21,24–27</sup> and negative<sup>21,24,26,28</sup> grief responses to three key foci: organ procurement, the decision making process, and the gift of life discourse. As an example of this work, Clerin and Zolen suggest<sup>21</sup> that consent to organ donation neither impedes nor advances grief reactions for donor families, but that decision making interactions with medical personnel have the greatest grief impact. Stouder et al<sup>23</sup> argue organ donation is a positive factor in the grieving process for families. There is minimal inquiry into the experiences of bereaved families who decide against donation.<sup>29</sup>

Some suggest the research on grief and transplantation needs to be more broad,<sup>5,26</sup> for it does not adequately explore the grief experiences of those bereaved by sudden or violent means.<sup>5</sup> They call for research that examines the *context* of grief. Calls have also been made for research to examine particular expressions of grief<sup>30</sup> related to transplant such as those in non-white and non-Christian communities.<sup>31–33</sup>

Patient experience may also be left out of the conversation around grief and transplantation.<sup>34</sup> In their 2010 practice review of psychological and psychosocial issues for transplant recipients, Rainer et al<sup>33</sup> argue the transplantation process may leave the recipient with a mixture of distressing experiences including depression, fear and grief. However there is a lack of attention paid and little legitimacy given to patients' subjective reports of their suffering.<sup>33</sup> After transplantation, patients are often encouraged to be grateful.<sup>35</sup> Yet they may feel gratitude mixed with grief for the donor.<sup>1,19</sup> Seldom are these mixed and complicated feelings given the attention they deserve in clinical heart transplantation research.<sup>36</sup>

### **Research question**

Consequently, this inquiry set out to explore not only what patients listed for and living with heart transplant said about loss and grief, but also how they expressed their embodied and often complex feelings. The research question was: What are the loss and grief experiences of patients waiting for and living with new hearts?

### **Methods**

This question guided a secondary qualitative analysis of audio-visual interview data<sup>1,35,37,38</sup> previously gathered by the team. The interdisciplinary team included a nursing academic, advanced practice nurse, transplant cardiologist, transplant psychiatrist, critical theorist of embodiment and bioethics, a social scientist of mental health and a social worker. For this project, the research team viewed and coded the audio-video interviews and transcripts, discussed themes and generated analytic categories.

### *Theoretical orientation*

In a direct departure from most clinical heart transplant research, the team's original visual methodology is oriented to the embodiment work of Merleau-Ponty, an existential phenomenological philosopher.<sup>1</sup> Merleau-Ponty demands a focus not only on speech, such as what research participants say

in response to questions or surveys, but also on what participants communicate with their bodies (for example hand gestures and facial expressions) at a particular time and place. This approach also focusses on intercorporeality or the physical (the transplanted organ) and emotional connections (kinship) between bodies, such as the heart donor and the recipient. Merleau-Ponty argues that changes to the body, such as those that come with heart transplantation, also create changes to the self and vice versa.<sup>39–44</sup> In short, this theoretical lens forces the researcher to go beyond numbers and words in exploring the heart transplantation process.<sup>45</sup> Using a qualitative visual method was the natural next step.

### *Qualitative visual methods*

Qualitative visual research covers a range of methods and practices that involve the use of visual media and technologies at all stages of the research.<sup>1,37</sup> Visual research is rarely purely visual, often involving the combination of visual, verbal and written methods such as in-depth interviewing, field notes or participant observation.<sup>1,35,37</sup> Although new in transplant circles, visual research has had a place in social sciences since the 1920's, with a branch developing in anthropology<sup>46,47</sup> and one in sociology.<sup>48–54</sup> The latter came to be known as visual sociology (now commonly referred to as visual methods) and may include the use of photograph specific approaches and digital film/video methods. Haw and Hadfield<sup>54</sup> divided video methods into five modalities including those that are more participatory and those that focus on *extraction* or using video to record a specific interaction, such as a research interview with transplant patients, so that it can be studied in more depth. The extraction method used to gather data in this study was also influenced by the qualitative visual methods developed by Heath,<sup>55–57</sup> who draws on the principles of conversation analysis to examine social interactions. Focusing on "*expressive gestures*"<sup>57</sup> for example, Heath examines how gesture and bodily conduct are used to "display, enact and (re)embody ... difficulties."<sup>57</sup> This process "... render[s] visible what would otherwise remain hidden and unavailable for inspection."<sup>57</sup>

Drawing on these approaches, a number of papers have been published that outline the method developed by the interdisciplinary team.<sup>35,38</sup> These papers detail how video has been used in concert with in-depth interviewing and field notes to examine the process of incorporating a transplanted heart, incongruities between participants' words and their embodied 'expressive gestures' as well as 'the obligation to say thank you' felt by many heart transplant recipients.<sup>1,35,37,38</sup> For this secondary analysis, the research team went back to the interview data once more.

### *Participants*

After approval from the Research Ethics Board at the hospital, the focused open-ended interviews were previously conducted in a non-clinical setting with 23 participants listed for transplant [52% male, mean age 51.5 ± 9 years; mean 7.4 ± 7.3 months on list] and 27 medically stable heart transplant recipients [70% male, mean age 53 yrs ± 13.77; range 18–72; mean time since transplant 4.06 yrs ± 2.42]. The patients had been identified by clinic nurse coordinators, were diverse in terms of culture and race, were English-speaking and had no documentation of cognitive compromise. One male and one female declined for unspecified reasons. Each patient signed an informed consent prior to participation. Patient interviews were anonymized. Each patient was given a numerical identifier that indicated if they were pre or post heart transplant (i.e. Pre-11).

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