

Families and Heart Transplantation: Reversing the Trajectory of End Stage Heart Disease

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Family caregiving is central in the heart transplant (HT) process.

Method: Using a constructivist grounded theory approach, study data were collected from 12 health professionals and 15 families in which one member was a HT recipient throughout three phases of the HT process.

Findings: Our interpretations suggest that family caregiving contributes to “reversing the downward trajectory” of end stage heart disease. This impacts the health of caregivers and disrupted family life. In some families, this caregiving work contributed to a smooth and uncomplicated recovery, while for others caregiving work was demanding and

prolonged, or their loved one succumbed. Families reported that access to system-level supports for family caregiving varied.

Conclusion: Family caregiving is an important factor in a successful recovery from HT. To ensure effective family caregiving, support should be available to family members in this role across all stages of the HT process.

Key words: heart transplantation, family, family caregiving, grounded theory

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La famille et la transplantation cardiaque—Inverser le cours de la maladie cardiaque au stade terminal

Les soins prodigués par la famille sont essentiels au processus de transplantation cardiaque.

Méthodologie. Les auteurs de l'étude ont employé une approche constructiviste fondée sur une théorie à base empirique pour recueillir des données auprès de 12 professionnels de la santé et 15 familles dont chacune comptait un greffé cardiaque, tout au long des 3 phases du processus de transplantation.

Résultats. Notre interprétation des résultats autorise à penser que les soins donnés par les membres de la famille contribuent à « inverser le parcours descendant » de la maladie cardiaque au stade terminal. Cette

situation a une influence sur la santé des aidants naturels et sur la vie familiale perturbée. Dans certaines familles, les soins prodigués par les aidants naturels ont contribué à un rétablissement en douceur et sans complication; par contre, d'autres familles ont trouvé ce travail exigeant et long, ou leur être cher a succombé à sa maladie. Les familles interrogées ont rapporté une certaine variabilité au niveau du soutien reçu par le système de santé pour les aidants naturels.

Conclusion. Les soins prodigués par les membres de la famille constituent un facteur important pour un bon rétablissement après une transplantation cardiaque. En conclusion, les membres de la famille devraient avoir accès à un soutien à tous les stades du processus de transplantation cardiaque, pour leur permettre de remplir leur rôle d'aidant de manière efficace.

Heart transplantation (HT) is a relatively recent treatment option for those with end stage heart disease (ESHD). The first HT was performed in 1967 (Barnard, 1967) in South Africa. Since then, improvements in the surgical technique, matching donors and recipients, procuring and transporting hearts for transplantation, and immunosuppressant therapy have resulted in 80% to 90% one-year survival rates, and approximately 65% survival at five years (American Heart Association, 2008; Taylor et al., 2003). Thus, there is widespread acceptability of the treatment, as a viable treatment

option for many people with ESHD (Cupples, 2000; Dressler, 1991; Porter et al., 1991; Tahan, 1998) with the quality of life of HT survivors reported as good (Molzahn et al., 1997). Foundational to the quality of life outcomes of HT survivors is caring that occurs within a web of social and professional relationships. Family caregiving is important throughout the HT process (Sadala & Stolf, 2008). However, the contributions of family caregivers and the impact of these contributions on the health of family members and the family across all stages of HT are not well

understood. Our purpose in this study was to explicate the social processes that impact the health of family members and the family unit across the phases of the HT process: preparation for heart transplantation, recovery phase, and rejoicing (or grieving) phase.

Families, health, and the heart transplantation experience

HT can relieve individual suffering and improve functioning of a disabled family member, yet the HT process is, in itself, a major stressor for patients and families (Brown, Launius, Mancini, & Cush, 2004; Collins, White-Williams, & Jalowiec, 1996, 2000; Haugh & Sayler, 2007; Hwang, 1996; Kaba, Thompson, Burnard, Edwards, & Theodosopoulou, 2005; Linden, 2000; McCurry & Thomas, 2002; Merz, 1998; Nolan et al., 1992; Paris & White-Williams, 2005; Rivard et al., 2005). Medical practices such as HT are referred to as *halfway* technologies (Mishel & Murdaugh, 1987) in that sophisticated technologies emerge from the science of the *physical*, but do not adequately address the related psychosocial issues (Bohachick et al., 1992; Mishel & Murdaugh). Once a patient is considered for HT, patients' and family members' everyday lives become organized and coordinated around the health care system, leaving them vulnerable not only physiologically, but also psychologically, financially, socially, and existentially (Castle, 2004; Linden, 2000; McCurry & Thomas, 2002; Tahan, 1998). Hence, the health and well-being of individuals and the family unit are affected by this highly technological medical intervention.

Researchers confirm that patients and families experience stress during the HT process, and that this affects the health of spouses (Dew et al., 1998; McSweeney et al., 1995; Porter et al., 1991). In fact, spouses experienced more psychosocial distress pre-transplant than their ill partners (Bohachick, Reeder, Taylor, & Anton, 2001). Lack of finances, lack of support, fear of spouses' death, carrying a beeper, uncertainty, and loss of control are just some of the stressors reported by patients and families (Buse & Pieper, 1990; Canning, Dew, & Davidson, 1996; Collins et al., 1996; McSweeney et al., 1995; Mishel & Murdaugh, 1987; Porter et al., 1991, 1994). This stress has serious health implications. In a study of physical health and well-being of 1,333 family caregivers at three times during the first year after transplant, it was found that 37% reported a worsening medical condition or perception of their own health (Dew et al., 1998). Similarly, one year after HT, spouses reported less satisfaction with their health and socioeconomic status and more satisfaction with family life than before the HT (Collins et al., 2000). Stukas et al. (1999) explored post-traumatic stress disorder (PTSD) of family caregivers during the first year following transplantation. They concluded

that being female, having a history of a psychiatric disorder, and low social support increased the risk for PTSD. Often, families move on to a better life, but some experience deterioration in family relationships and health (Bunzel, Laederach-Hoffman, & Schubert, 1999; Burker, Evon, Loiselle, Finkel, & Mill, 2005; Burker et al., 2006; McSweeney et al., 1995).

Investigators suggest that stress is experienced differently across various stages of the HT process, such as the evaluation stage, the waiting stage, the surgical phase, and the recovery phase (Collins et al., 2000). Many researchers suggest that the waiting phase is the most stressful. Buse and Pieper (1990) reported that spouses perceived the pre-transplant period had a greater overall influence on their lives and relationships than the post-transplant period. Although the spouses' impressions of the post-transplant period were significantly more positive than the pre-transplant period, no significant differences in stress scores were found in these periods. In other studies, spouses reported the pre-transplant time as the most stressful period (Collins et al., 1996). Spouses who worked found the experience particularly stressful in both personal and socio-economic areas of their lives. Family members of HT candidates were found to use more coping strategies in the waiting-for-a-donor period than normative subjects did (Nolan et al., 1992).

The complexity of family support is evident. Families provided emotional and instrumental support, but worrying and over-involvement of families were also identified as sources of stress in a Canadian study (Hirth & Stewart, 1994). Spouses of HT candidates put their lives "on hold" during the waiting period, "tabling" life's activities for an indefinite period of time in order to devote themselves to their partner (Williams, 1991).

Investigators addressing families and HT focus primarily on the patient and spouse. To date, there is a paucity of research that explicates the web of social processes both within family (defined more broadly than patient and spouse), and between family members and health care providers. Describing and explicating the effect of these social processes on the health of family caregivers and the family unit may raise awareness and catalyze changes in policies and practices. Such changes have potential to improve the health of all affected by HT.

Methods

Design. Grounded theory, the method used for this study, is a qualitative approach designed to explore social processes and meanings toward building mid-range theories that explain social phenomena (Charmaz, 2006; Glaser, 1978; Strauss & Corbin, 1998). Grounded theory has evolved since its inception 35 years ago. Currently, the work of grounded theorists

can be located on a continuum of ontological and epistemological positions ranging from classic (Glaser, 2002) to constructivist (Charmaz, 2006). The theoretical formulations in this research are aligned with social constructivist positions on grounded theory explicated by Charmaz (2006). In a constructivist grounded theory, the theoretical analyses are held to be an "interpretive rendering of reality, not objective reporting of it" (Charmaz, 2005, p. 510). When using a constructivist grounded theory, the researcher uses grounded theory guidelines as a tool, but does not hold to the objectivist, positivist assumptions of classic grounded theory (Charmaz, 2005).

The interviews were guided by the research question arising from the literature review: *What is the web of social processes both within family (defined more broadly than patient and spouse), and between family members and health care providers that affect the health of family caregivers and the family unit.* The health of family caregivers for the purpose of this study is conceptualized holistically and, thus, encompasses the physical, mental, emotional, and spiritual (Young & Wharf-Higgins, 2008). In this study, family health is envisioned as constructed through family practices and processes that foster and support individual members' health (Young, 2002). Thus, family for the purpose of this study is defined as including those individuals identified as family members by the HT recipient and his or her primary caregiver whose involvements are implicated in the practices and processes that foster the health of individual family members. As family is the basic socio-economic unit of society at the interface between society and the individual, it is what occurs at this interface that determines what resources are available for family members' health and, thus, this interface is implicated in family health (Young, 2002.).

To begin the interview, an open-ended question was posed to open a space for participants to reflect on their experience of heart transplantation at the particular phase during which the interview was held. Further questions were posed to flesh out the details of how the HT experience impacted the health of family caregivers and the family unit with a view to surfacing individual health issues, family practices and processes, and practices and process at the interface between the family and the health care system that impacted individual health experience. As categories and relationships between categories were constructed and labelled during data analysis, additional sources of data that had potential to enrich the analysis were identified and pursued, for example, genres of family and health professionals. Further, as data analysis progressed, questions were crafted to more fully flesh out the description of categories and relationships arising toward constructing an enriched description of the web of social processes.

Participants. Participants were members of a family in which one member experienced the HT process. Family in this study was defined as those individuals perceived to comprise the family from the perspective of the heart transplant recipient (Weigel, 2008). Theoretical sampling was the technique used to identify participants knowledgeable and articulate about the family experience of the HT process and to ensure that rich and meaningful data were gathered. A nurse in a Canadian metropolitan tertiary care hospital was central in referring patients and families to the study. Data collection occurred between 2001 and 2005. Enrolment was prolonged, as it took time to enroll an adequate number of families representing diversity into the study. The study nurse provided potential participants with an information letter and, if they agreed to hear more about the study, a research assistant met with them to provide detailed information about the study and to answer questions and address concerns. Informed consent was obtained from all participants at the time of the initial interview. At each visit, the consent process was revisited and participants were reminded of their right to withdraw. With regard to children, the purpose of the research, voluntary participation, and right to withdraw was explained in simple terms with time designated for the children to ask questions. Children aged eight and older, and their parents, signed the consent form (see Hurley & Underwood, 2002, for guidelines for consent from children). There were three children in the study, one of whom was under eight years. For the child under eight, the study was explained to the child, questions were invited, the right to not participate or to withdraw at any time was made clear, and the parents signed the consent form on behalf of the child. Participants were all English-speaking.

As data collection and analysis progressed, families were approached that represented diversity with regard to geographic area, family type, ethnicity, socio-economic status, age, and phase of the HT process to maximize variation in the data. As data were gathered and analyzed, decisions were made about what further data, including people and other sources of data, would enrich the interpretation of the developing categories and relationships between them. Of the 15 families enrolled in the study, the majority participated in three or four in-depth interviews that occurred prior to and up to one year following HT. In total, 38 interviews were conducted with families during the study period. Thirteen of the HT recipients interviewed were male and two were female. They ranged in age from 24 to 71 years, with a mean age of 52 years. Nine of the families interviewed had children; two of these families had dependent children ranging in age from five to 18. Eleven families consisted of married partners, two were separated or divorced, and two

were single. Those individuals who were single relied on their parents or friends for support throughout the heart transplant experience. Thirteen families were Caucasian and two families were of South Asian heritage. Eleven families lived in urban and suburban communities in reasonably close proximity to the heart centre, while four families lived in four different small communities located at a distance from the centre. Every effort was taken in this study to ensure diversity in the sample in terms of geographic location, family type, gender of HT recipient, and ethnicity.

Twelve health care professionals from a range of disciplines participated in the study to add breadth and depth to the analysis. The health professionals were sent an information letter and were invited to contact the research assistant if willing to hear more about the study. Those who participated in the study included staff nurses, clinical nurse educators, a social worker, psychologists, cardiologist, and a cardiac surgeon. Male and female genders were represented in the health professional group.

Data collection. Patients and families who had experienced the heart transplant process were interviewed in the hospital, as well as in their homes. Each “family” participated in one to four group interviews that were one to two hours in duration. The interviews occurred at various phases of the heart transplantation process (waiting for a donor, the surgical procedure phase, and three, six, and 12 months following the surgery), with one interview per family per phase. The children were invited to participate in the interview by drawing a picture of their experience while talking (see Whiting, 2009). Health professionals were interviewed in their private offices or in a private space in the hospital. The 12 health care professionals each participated in one interview approximately one hour in length.

Interviews were audiotaped and transcribed. Data were entered into NUD*IST (QSR International, 2000). Immediately following each interview, the researchers audiotaped field notes in which details of the place and people were noted, as well as reflections and



Figure 1: Child's drawing from the heart transplant interview.

intuitions. The field notes were transcribed and became part of the data. As well, analytical memos were recorded and transcribed following interviews and during data analysis.

Ethics approval for the study was obtained from both the hospital's research ethics committee and the university's human research ethics board.

Data analysis. In grounded theory, analysis begins as data are collected. As complete transcripts of the family interviews were received, they were read by members of the research team to get a sense of the whole. Then the transcripts were considered line by line for key words and phrases that eventually became shorter code phrases. Using constant comparison and asking questions related to the data, the shorter phrases became categories and sub-categories used to organize data in the software program NUD*IST v3 (QRS International, 2000). A review of the categories and sub-categories enabled linkages between categories to be constructed. Once the linkages were articulated, the statement of a core category, the basic social process, was written (see Charmaz, 2006; Chen & Boore, 2009).

Constant comparative analysis, as described by Glaser (1978), and Strauss and Corbin (1998), and further explicated relative to constructivist assumptions by Charmaz (2006), was applied in the analysis. Constant comparative analysis is a process in which data from different participants and data sources are compared. Data are examined relative to each other and to categories arising, a process that leads to gaining insight and asking new questions and guides theoretical sampling (Birks, Chapman, & Francis, 2006; Charmaz, 2006; Glaser, 1978). Memo writing was used to spark conceptual thinking during initial coding and to guide theoretical sampling (Charmaz, 2006; Strauss & Corbin, 1998). Theoretical sampling fills gaps in the developing analysis, thus ensuring depth in the analysis and a thick description of categories (Charmaz, 2006; Strauss & Corbin, 1998). As the analysis unfolded, higher order concepts and relationships were developed. Categories identified during early coding included tensions, tolls, tragedies, and triumphs. Higher-level themes were then labelled: Journey, Work, and Outcomes. The process of explicating themes and relationships culminated in identification of a basic social process, that is, a statement of how the categories and themes arising fit together toward new understandings of the social processes of concern (Charmaz, 2006; Glaser, 1978; Heath & Cowley, 2004; Strauss & Corbin, 1998). Specifically, the basic social process, "the family work of reversing the downward trajectory of ESHD", was named.

Rigour. As the data collection and analysis proceeded, the developing theory was confirmed with participants during research interviews. An audit trail was kept of

decisions made in analyzing the data. The data gathered during the interviews with 15 families and 12 health professionals enabled us to construct a rich description and meaningful analysis.

Findings

Heart transplantation both impacted and involved family members. Attaining wait list status was a defining moment for families in which one member has end stage heart disease. Prior to this "moment", families endured an intense period, often prolonged, of dramatic change in health status of their loved one. One couple tells their story:

Man/father/husband: I was diagnosed with cardiomyopathy [about nine years ago] and managed quite well until one day. We were walking and kibitzing and fooling around and I turned around to get a drink and I went down.

Woman/mother/wife: ...he went into full arrest... firemen, paramedics, then cardiac paramedics... they were warning me that it was serious. He had gone blue [and was] intubated when I got to the hospital.

A few days later, the doctor came in and said, "Your heart is in really bad shape and we think you might have to start thinking about transplants". Well that just floored us. It was the last thing on our minds. Then we started all the tests. After they had done the tests they decided that he was not going home until they got him a heart. We were really worried for a while because he had a lot of high pressures in his lungs and they weren't putting him on the list for transplant and it was only two weeks ago tomorrow that they put him on the list.

Man/father/husband: So, it took a couple of tough months.

Woman: So that was such a relief. We are officially on the list and they said; "Now the real waiting begins".

The work of reversing the downward trajectory of end stage heart disease occurred through three stages: preparing for the transplant, recovering, and rejoicing (or grieving). These stages crossed the boundaries of home and hospital, often involved relocation of family members to a different city, and intruded on everyday family life, sometimes to the extreme. The shape of the upward, reversed trajectory differed from family to family largely depending on the level of health and functioning of the family member with the diseased heart. While most families in the study were successful in reversing the trajectory, two families lost a loved one during the waiting period. One person, a recipient who had expressed considerable concern for his health during the interviews that occurred following his discharge from hospital, suffered from marital breakdown in the course of the heart transplant process.

Preparation for the heart transplant. The preparation phase began when the potential HT recipient was placed on the waiting list and lasted until either the recipient died or received a heart. Once the candidate was “listed”, the family entered into a waiting period that some families referred to as “waiting for the beep”. During this time the family member with the heart condition became increasingly fragile, in some cases requiring prolonged hospitalization. A drawing by one of the children captures what it is like as a family to wait (see Figure 1). In the drawing, the family members are seated around the room, Mom and two children are on one side of the room and the father (who is on the wait list) is seated beside the third and smallest child. On the wall behind the father is a clock marking time. Behind the family and between the artist and the father is a doorway, an entrance to a looming black space. For us, as analysts, this drawing captured what it meant to be living in a space between hope and doom, a space dominated by a ticking clock.

For some families it was a long, trying wait for the beep while for others, it was a rushed process.

HTR: This was the second time I thought about going on the list. Last time 12 years ago. They gave us three months to think about going on the list this time. I was reluctant to have it. A guy had to die for me to live and that bothered me. I had quite a psychological problem with it for a while. Then I got real sick and there was no choice. I'd better go on the list.

Wife: He was on the list and we didn't have time to think about it. Everything went so fast that before we realized it, it was done.

During the wait, family members came to grips with the reality of the loved one's failing health, possible death, and the concurrent promise of near-full recovery. The trajectory of the chronic illness was often unstable. The illness spiraled downward slowly in some cases, or rapidly in others, with the ill family member experiencing health-related incidents that contributed to an ever-fragile physical condition, or death. In some cases, the surgery happened so quickly it was a blur. Families told us that during this preparation time, it was important to them to maintain a sense of “normal” family life while turning to each other, friends, supportive communities, and belief in a greater power (often God) to manage the challenges of waiting.

Some families told us of their experience of one or more “dry runs”. A “dry run” is the label given to situations in which the patient is called for surgery, but the procedure is aborted because the heart is not suitable. One heart transplant recipient recounted his first dry run:

They had all the IVs hooked up, ready to go to the OR when the doctor phoned up and said: “I'm sorry, I'm having my first look at the heart and it's not satisfactory. And all the

people present looking after me, I thought they were going to cry. All the nurses, several doctors came up to me. They were putting their arms around me. “I'm sorry we're putting you through this”. And I thought, “Jeez, it's all right. Catch you next week.” And I think the empathy they showed was really impressive...

Another tells of his experience:

...18 months is a long time and four dry runs... first call came in, I thought it was nothing, second call that wasn't too bad, but I had to say the fourth I found it very, very hard... physical and mental effects... I went on anxiety drugs...

Challenges during this time that create tensions within the family included dislocation and hospitalization of the loved one and the sometimes-related dislocation of the family caregiver; worrying about, supporting, and caring for a family member in failing health; and dealing with the complexities and demands of the health care system and relations with health professionals. Passage through this phase was affected by the suddenness of onset of end stage-heart disease: the particulars of family life, for example, presence of dependent children, stability of family structure, the family's economic status, and the proximity of the family home to the tertiary care facility. One health professional observed a couple dealing with the prolonged hospitalization of the husband prior to the heart transplant. He recounted:

It was a very difficult time for them. Very, very difficult. The wife just didn't know how to handle this at all. Her husband was at the point of getting quite upset because he wanted her to be part of his life, but didn't know how to make that happen. As he waited, he got sicker and sicker... it was very difficult to watch.

Further influences on safe and timely passage through this waiting phase include the medical, empathic, and communication skills of health professionals, health care system issues, such as the availability of quality donor hearts, and the capacity of the system to provide professional support for patients and families, as they wait for the heart transplantation. A nurse educator commented on the importance of advanced preparation for the procedure:

He was waiting for a transplant for four months and finally got his heart... he'd learned everything he could about transplant... he went home in 9 or 10 days and is doing remarkably well.

The family work involved in waiting for the heart transplantation took a tremendous emotional, physical, and financial toll on the family. Some heart transplant candidates went on to an untimely death, a shock for family members who hold onto the promise of a successful HT and a concomitant bright future.

Recovery phase. Following heart transplantation, the HT recipients (HTRs) began the climb up the “trajectory” with family members providing support and encouragement. Hospitalization following surgery could be relatively short or prolonged. In some cases, repeat hospitalizations occurred. The tensions that take a toll on family members in this phase relate to setbacks in recovery; travelling to and making time for follow-up biopsies; other health-related appointments, cardiac rehabilitation, and diabetic clinics; the quality of relationships with health care team members, lack of confidence in the skills of the health care providers, especially nurses and physicians; if dislocated, the stay in the city; family issues such as childcare, finances, juggling hospital visits with work; and, managing spousal intimacy. An account of a nurse was particularly revealing in terms of how hospitalization affected one couple’s intimacy:

His wife was having some very bad difficulties being away from him for so long... she was getting jealous imagining that there were romantic things happening with the nurses... she [the man’s wife] would say that she was totally ignored, that no-one even knew her name.

In contrast, the family of another HT recipient man reported that:

...the support here has been excellent. All the nurses have just been super... hands-on hugging us and supporting us...touchy, compassionate. On both floors, there were nice nurses and lots of support.

Family members noticed and were affected by how they were treated by nurses. Returning home after hospitalization was a time of healing and adjustment for the recipients and their families. Some of the challenges for patients during this phase included learning to manage a complex medication regimen, experiencing and managing the symptoms and side effects from multiple new medications, dealing with fatigue and sometimes confusion and pain or soreness, frequent assessments including invasive and disturbing heart biopsies, and orchestrating participation in a cardiac rehabilitation program in the context of managing numerous other challenges and/or having to travel a distance to the rehabilitation program. These challenges often required attention, caregiving, or the participation of a family caregiver, most often a female spouse.

Spouses generally assisted or took charge of the medication regimen and accompanied their partners to the hospital for assessments and cardiac rehabilitation. One woman’s words captured the emotional investment and teamwork that occurred relative to the medication regimen:

We’ve got a good system now for taking them [the medications]... he’s only forgotten them once... he’d gone to hockey and I’d take the pills out after dinner to see what was there and the pills were still sitting there... so I dashed over to the ice rink and there I am in the penalty box waving at him to come and take his pills...

At the one-year interview, one woman was still managing the medication regimen of her husband. As one of the psychologists in the study observed, “post-transplant they really [patients] need to have a worthy coach in place.”

Speaking to the ups and downs experienced during the first year following the heart transplant, one wife of an HTR commented:

There’s always very highs and there’s lows. Right now, we’re in a bad bout, so I called the cardiologist on call on the weekend, and he prescribed a different sleep medication... At night when he is not sleeping, I am not sleeping and we just don’t have any long periods when there is not something strange happening. Eventually, they will become blips further apart ...so I have cut work back to three days a week.

This pattern of reconfiguring daily life to accommodate the health issues resulting from heart transplantation was evident in many families. However, one socially and economically comfortable, retired couple reported that at a year following the surgery, life was fully back to normal in terms of their capacity for socializing and physically challenging activities such as tennis, an activity that they had long enjoyed prior to the husband’s heart condition.

Some couples found new meaning in this recovery phase by appreciating family life in new ways or reclaiming or strengthening their religious affiliations.

HTR: I think it makes you a better person. It makes your life more meaningful... you’re giving back something that you have received... not only [the heart], but a lesson you learnt.

His wife added: And I think it gives you hope... it gives you a new life, to which the heart transplant recipient responded: And I have more appreciation for my wife and my sons, but mainly for her.

During the recovery phase, in most cases, the heart transplant recipient was primarily focused on healing. Thus, family members shouldered full responsibility for managing the everyday details of the household, including childcare where relevant, and managing the financial situation of the family. A spouse spoke of the “work” involved in assuming a supportive role:

They show the patient about the meds, but they don’t show the spouse. When he came home, he was not really “with it”, so I had to do a lot of reading [of printouts about the drugs]... he was on 44 pills... I think the caregiver at home should be there for the medication teaching...

The complexity of some family's lives often made recovery more challenging. One recipient in his 50s remarked:

My health is not completely stable... I feel good sometimes, then it gets knocked back down. I get a low-level rejection and we fix it up.

This man's family situation was challenging for him, as he was not only a single parent because of his former wife's alcoholism, but also he was supporting a grown son who was hospitalized for lower limb paralysis. When we met one year post-transplant, this man, his disabled son, and the man's parents met with us. Reflecting on his situation, the HTR remarked:

But my biggest concern is [wife's name] drinking and the risk it was to the children. I have a nasty habit of waiting 'til the bitter end to seek medical help... because I wanna be with my children.

His disabled son said: People would say, "Well, what if you don't walk again". I say I will deal with that when the time comes. If I could erase one thing that's happened in our family, this would not be it, I don't think it would be my Mom's drinking either. I would like to make Dad better, because he is the last person on earth to deserve to get sick.

In contrast to the depth of commitment of this son to his father's recovery, the HTR's 80-year-old mother was more focused on the stories of the man's former wife's alcoholism to the point that the HTR said to his mother during the interview, "I guess that's enough stories". This man's recovery was complicated by overwhelming family issues that interfered with his capacity to care for himself.

Recovery took time both for healing and reflection on the organ donation. Families told us that during this time they thought about the donor, the gift of a heart, and the concomitant loss experienced by another family. Hearsay from hallway talk in the hospital, information gleaned from "detective" work, and/or news reports to identify the donor played in their minds during this reflective time.

HTR: The doctor told me I had a heart from a man in the Portland area.

Wife of HTR: We get this file, a binder, to take from one place to another in the hospital and while we were waiting, I was flipping through it, probably I wasn't supposed to. It does say the donor and recipient.

Family members thoughtfully considered how to thank the family for their precious gift. One wife of an HTR shares her story of writing a thank you letter from her family to the donor family:

I am the scribe. I came in here [the living room] and closed all the doors and turned off all the music. It had been bothering me that we had not thanked them. When my

husband got sick, the mother of a friend gave me a beautiful glass heart and told me to hold on to it until you get your new heart and then send it to the donor family. The nurse clinician wasn't sure how that would go over, but then she read my letter and said, "OK we'll send it"...

Some participants talked about attending an evening memorial service for donor and recipient families to come together in gratitude and remembrance. Pictures of the donors were displayed at the front of the church with a candle lit for each donor. Following the service, tea, coffee, and cookies were served in the basement of the church where donor family members and recipients and their family members met and talked. Reflecting on his attendance at this service, one heart transplant recipient observed:

When we went to the memorial service, we realized that there are people there who wanted to know what became of their loved one's organs. And this fellow, in particular, was searching to see who had received his daughter's heart and he said it wasn't so much the other organs, but he really wanted to know what happened to her heart.

Writing the letter and the memorial service were noteworthy emotional events for the recipients and close family members during the first year following the surgery.

The recovery of recipients followed different trajectories. While some HTRs returned to their pre-illness state including partial return to paid employment, others experienced a moderate recovery in which the recipient lived a full life, but was unable to work for pay. Still others recovered only to the extent that they had capacity to live an independent, everyday life with only minimal family caregiving.

Participants talked about learning to live with their situation and commented on the central role played by health professionals in this learning process.

Wife of HTR: The nurse [name] helped us work into this idea of transplant and all the staff, really. Whenever you have questions they help you.

One couple summarized what helped them through this phase:

HTR: If we demanded anything, they helped us right away.

Wife: Everything we needed was there and people helped and there was no problem.

Recovery from the heart transplant was a process that varied from person to person and family to family. Competent caring family members and health professionals were key players on this journey of recovery. For many, during the year following the HT, there was a turning point in the recovery such as being weaned from medications that marked a time to enter into a new way of being.

Rejoicing (or grieving) phase. As the HTRs regained strength and vitality, a sense of excitement grew and celebrations happened. The primary family caregivers increasingly reclaimed a life of their own—former interests, hobbies, and community involvement, restful sleep, rewarding work outside the home, and social outings. They talked about enjoying life with friends and other family members, rather than leaning on them for support. Thus, the impacts of the HT process on the family caregivers and the social isolation they had experienced because of their caregiving role began to wane. Celebrating new life meant, for some, reaching out to new communities or to old communities in new ways. A number of families experienced a rebirth or reclamation of religious faith. One family held a celebration event at the one-year anniversary of the heart transplant.

On the anniversary of the heart transplantation, we invited everyone in the community who helped along the way to a party... people who had driven the kids to hockey or made food or whatever, and the kids' friends... 96 people... we called it a Heart Party and everyone came with gifts and heart-shaped balloons... we celebrated it as a milestone.

Another recipient talked about this phase in terms of closure:

With this heart transplant for 15 to 16 years under a doctor's care with a heart problem, right now I can say that there is closure. Once we have clearance from the doctor, we are going on a road trip across Canada.

The journey through the heart transplant experience was emotionally and physically taxing for HTRs and committed, loving family members. Health professionals played an important role in mitigating the stress and uncertainties of the procedure by responding effectively to questions, offering and extending support and compassion, and providing competent, timely care to not only the HTR, but also key family caregivers.

Discussion

Family work to reverse the downward trajectory of end stage heart disease throughout the HT process is the basic social process of this grounded theory study. This family work takes a toll on family members' health and creates tensions in families. When families enter the HT process, our findings suggest that tensions arise from disruptions to their usual ways of being. Examples of such disruptions include the hospitalization of heart transplant recipients in distant tertiary care settings, serial "dry runs" that seriously disrupt the usual flow of family life and emotions, and clinic appointments and cardiac rehabilitation that require frequent and regular travel to the tertiary care settings, often from a considerable distance. Likewise,

families of HT recipients are often present and require support and resources in a health care system with health professionals who may not be predisposed or skilled to address their needs. These findings are similar to those of other researchers (Canning et al., 1996; Collins et al., 1996; Hwang, 1996; McCurry & Thomas, 2002; Mishel & Murdaugh, 1987). Historically in acute care settings, the focus of professional care is to "cure" the *individual*, as two professional participants pointed out, noting that there are explicit and implicit rules shaping individual-focused practice. Nonetheless, many practitioners across professions are deeply empathetic with the needs of families. However, given the historic focus on the individual in acute care settings, professionals have few resources to meet the needs of families.

Reversing the trajectory of end stage heart disease is an intense journey for the recipient, family members, and health professionals. We note in our findings a discontinuity in the valuing of the work of families in HT arenas. Family caregivers play a central role in ensuring that the outcomes of HT are successful. When an individual is assessed for HT, family support is a criterion for acceptance of the potential recipient onto the wait list. However, few formal resources are in place to support families for their caregiving work. That family members change their job status to care for the HTR throughout the trajectory of the illness and recovery, (such as going to part-time from full-time employment, transporting the HTR to follow-up appointments) points to serious economic impacts of the HT process on families, as a unit and family caregivers.

Family caregivers in our study played a key role in ensuring that the HTR followed the complex medication regimen, especially when the recipient was dealing with consequent cognitive issues. Both families and health professionals ultimately benefit from each other's contributions to care. That the work of families is largely invisible is likely rooted in the historical practice of valuing work that is public and taking for granted work that occurs in the private family sphere (Bunting, 1992). We noted that tensions such as those presented above take a toll on families, as units, and on individual family members. The extremely compromised health of their loved one and the demands of waiting for a transplant and the hospitalization during and recovery from HT introduce a level of worry and uncertainty into the family that changes the family's usual way of being.

Our findings resonate with Bourdieu's idea (1980) that agents "cut their coats to fit the cloth" with families making, in some cases, extreme accommodations to meet the demands of the heart transplant process such as graciously accepting sequential "dry runs"; travel to

a large city for extended periods of time with associated costs both financial and personal, significant changes in family caregivers' paid employment, with the associated change in economic and social status, and changes in usual social and recreational patterns, for example, childcare and sports. Simultaneously, families enter a period of intense interaction in health care arenas where they may or may not be met with empathy and supportive care. These tensions played out for some family members in health consequences such as sleep disturbances, extreme anxiety, and changes in work/school performance. All family units and family caregivers in our study were stretched economically and taxed physically prior to surgery and thereafter for at least six months following surgery.

To address this inequity and the health sequelae for family members, we recommend that health professionals continue to develop focused approaches to the care of family and family members of HT recipients. The variation with which professionals extend care to families in the HT field suggests to us the need to ensure that all professionals are academically prepared and have the resources to skillfully and compassionately address the needs of family members. With health professionals working so closely across disciplines in the care of these families, there is a need for diligence to ensure ongoing dialogue within and across professions regarding a coordinated approach to support the health and well being of the family and its members, as they contribute to the caring process. Educating health professional students in an inter-professional context to the development of knowledge and skill for family care would contribute to ensuring a consistent response to families of HT recipients across and within disciplines and settings.

Family caregivers, of whom the majority are women, should be engaged in conversations at the outset regarding the demands of caregiving, including how caregiving might affect their pursuit of economic and career goals (Young & Little, 2004). Thus, family caregivers are provided with the opportunity to make an informed decision about assuming this demanding caregiving role. Health professionals need to be sensitive and responsive to the extreme disruption to usual family patterns with a view to ensuring that resources are allocated to mitigate the effects of the procedure on family life and on the health of family members. Romanow (2002) called for recognition of family caregivers noting that various forms of support could be instituted including direct remuneration or tax concessions, job protection, respite, and caregiver leave. Such policies, if applied in the HT field, would assist families to manage family disruptions. Further, we suggest that family caregivers need to be valued for their immense contributions to the heart transplant

process. While policy-level solutions, as proposed by Romanow, would go some way to reifying the value of family caregiving, less formal rewards instituted by organizations, for example, designating days to celebrate family caregivers, providing rooms in hospitals where family caregivers can replenish energy and spirit, and having affordable accommodation available for the periods HTRs and their families require care away from their home communities. Further, the development of peer support programs where the HTR and family members receive support and learn from the similar experiences of others would be valuable throughout all phases of heart transplantation. This coaching and support has been effective in the care of other organ transplant recipients (Starzomski & Hilton, 2000).

It was evident in participants' accounts that spiritual and religious supports were essential for coping. Similar observations have been made elsewhere. For example, Loeb and her colleagues (2003), in a qualitative study, reported that relying on spirituality and/or religion was an important strategy employed by the 37 older adults in the study when managing multiple chronic conditions. In a qualitative study exploring the needs of patients and families during the wait for a donor heart, Haugh and Saylor (2007) identified spirituality as a key coping strategy. Koenig (2002) reported that there have been 724 studies on religious coping this century, and about two-thirds of them have demonstrated a positive association between religious activity and better mental health, greater social support, and less substance abuse. In a number of studies, relationships have been found between quality of life and spirituality (Bartlett, Piedmont, Bilderback, Matsumoto, & Bathon, 2003). This suggests that members of pastoral care teams are important in the provision of family care, and that nurses should consider the spiritual needs and strengths/supports that family members have in their assessments and provision of care.

If health professionals' social mandate is indeed to address the health of people, then the scope of practice in the HT arena needs to encompass caring for the caregivers of heart transplant recipients, since caring for a family member undergoing HT takes such tolls on family members' health. Further, if a health profession such as nursing takes a holistic or systems view of health, where it is envisioned that health is constructed through a web of social and environmental influences, then the family unit enters into the scope of practice. Such a health professional could assess the tensions created by the HT process on families and family members toward ensuring family access to instrumental and emotional support in support of health.

Further research regarding interventions to address the psychosocial and emotional needs of both transplant recipients and their family caregivers is warranted across all stages of the HT process. Also, further study of the social and professional contexts of care for people affected by HT is important to improve care. Participatory action research could be a useful approach in this regard. In addition, as participants in this study were English-speaking, it is important that future research include recipients and family members who do not speak English to reflect the ethnocultural diversity of the heart transplant population.

Limitations

As in all studies, this research was limited in several ways. While every attempt was made to ensure maximal variation in the data (for example, participants represented urban, suburban, and rural people and we attended to age, gender, and ethnicity in seeking participants) only English-speaking people participated in the study. Women were less well represented than men in the sample, likely a reflection of the social inequities in the HT field (see Young & Little, 2004.) In addition, all participants came from one centre and, thus, were subject to centre-specific policies and practices.

Conclusion

HT allows for the previously unimaginable. Given new hope, families embark on a highly charged emotional journey. By giving attention to family members and the

family unit, nurses and other professionals can play a key role in supporting families through this sometimes hopeful, sometimes heart-wrenching and always demanding challenge. Health professionals must ensure that family caregivers can access the resources they need to maintain their health and the integrity of the family unit under the strain of supporting their loved one through the heart transplant process. Finally, health care professionals working in HT arenas must envision family members as part of the HT team, acknowledging the centrality of family caregivers in the process. ♥

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