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Meaning and life purpose: The perspectives of post-transplant women

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PURPOSE: A descriptive, exploratory study was conducted to examine perceptions and meanings assigned to the experience of end-stage heart failure and transplant surgery in female recipients.

METHODS: Data was collected from 33 female heart transplant recipients from a heart transplant clinic using quantitative and qualitative methods. Women completed the Life Attitudes Profile and Multiple Affect Adjective Checklist and participated in a semi-structured interview.

RESULTS: Women on average had a meaning score of 30.64 ± 8.32 (range, 10-43) and a life purpose score of 40.12 ± 13.78 (range, 17-63). The participants reported high levels of anxiety, depression, and hostility. Women expressed feelings of fear and lack of control related to their heart disease and transplant; however, they also described optimism, faith, acceptance, altruism, self-transcendence, self-fulfillment, and changing life goals as strong motivators for recovery.

CONCLUSION: Women experience emotional distress as much as and beyond 5 years after heart transplantation. Their sense of meaning and life purpose is relatively high and is positively informed by several motivating factors that serve as coping resources throughout the recovery process. (Heart Lung® 2003;32:250-7.)

A growing body of evidence supports the notion that heart transplant recipients experience varying levels of psychological distress during recovery from surgery.¹⁻⁴ persons who undergo heart transplant experience increased psychological distress related both to postoperative physiological changes and to adjustment to a post-transplant treatment regimen fraught with side effects.⁵ Recently, researchers have suggested that the need to cope with the physical loss of a heart and acceptance of a donor heart may be antecedent to feelings of psychological distress.⁶

To date, little research has addressed how recipients perceive their transplant experiences and the impacts on their lives. Furthermore, the majority of studies^{6,7} focus on men or have a limited number of

women in the sample, restricting the generalizability of findings to women. Given the increasing number of women undergoing heart transplant surgery⁸ and earlier reports that female gender is an independent risk factor for increased psychological distress after heart transplantation,⁹ it is important to characterize the experience of women. The purpose of the current study was to explore women's psychological recoveries from heart transplant surgeries using both quantitative and qualitative methods. The specific research questions were:

1. What is the level of meaning, life purpose, and psychological distress of women after heart transplantation?
2. What is the relationship between level of meaning, life purpose, and psychological distress in women after heart transplantation?
3. What perceptions do women have related to their experiences of heart failure and heart transplant surgery?

METHODS

Study subjects and data source

The setting for the study was a single, outpatient post-transplant clinic affiliated with a tertiary uni-

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versity-affiliated medical center. Following approval by the appropriate Institutional Review Board, 33 women who had participated in a parent study¹⁰ were asked to participate in this companion study. The inclusion criteria for study enrollment were the following: female gender; post-transplant status; oriented to time, place, and person; ability to read, write, and speak English; and willingness to participate in a semi-structured interview. Women from diverse socioeconomic backgrounds were purposively recruited to provide different perspectives and to help avoid the possibility of elite bias in which only the most articulate, who tend to be of higher socioeconomic status and members of a dominant culture, are represented.

Procedures and instruments

Patients were recruited to participate in the study through flyers posted in the post-transplant clinic. A research nurse provided women who expressed an interest in the study with information related to study procedures. After obtaining informed consent, the nurse scheduled home visits with the participants to conduct the face-to-face interviews with the women in the privacy of their own homes. At the time of the home visit and before participation in a semistructured interview, the women were asked to complete two self-administered questionnaires: the Life Attitude Profiles and the Multiple Affect Adjective Checklist (MAACL).

Meaning and life purpose scores were obtained from the existential vacuum and life purpose subscales of the Life Attitude Profile.¹¹ The existential vacuum subscale measures lack of meaning in life, lack of goals, and free-floating anxiety; it is comprised of 7 items. The life purpose subscale measures zest for life, fulfillment, and satisfaction and is comprised of 9 items. Each item for both subscales is measured on a 7-point Likert scale from 1 (very strongly disagree) to 7 (very strongly agree) with possible scores ranging from 7 to 49 and 9 to 63 for the existential vacuum and the life purpose subscales, respectively. Scores for the existential subscale were recoded to reverse negatively worded statements. Total scores for the subscales were computed by adding the score for each item; higher scores for both subscales denote higher (better) perceptions of meaning and life purpose. The existential vacuum subscale has satisfactory internal consistency ($\alpha = 0.81$) and stability (test-retest $r = 0.81$).¹² The life purpose subscale is internally consistent ($\alpha = 0.83$) and stable during a 1-month period (test-retest $r = 0.83$).¹²

The MAACL was used to measure 3 mood states of participants: anxiety, depression, and hostility. It is composed of 132 alphabetically arranged adjectives; *plus* items are scored if the participant checks them, and *minus* items are scored if the participant does not check them. This method of scoring provides a partial control over response set.¹³ Scores for anxiety, depression, and hostility range from 0 to 28 (norm ≤ 7), 0 to 40 (norm ≤ 11), and 0 to 28 (norm ≤ 7), respectively. Higher scores reflect higher levels of dysphoria.¹⁴ The reliability and validity of the MAACL has been demonstrated in patients with chronic heart failure.¹³

During the actual interviews, women were asked to describe perceptions they had related to their illness or health condition and how their experiences (including heart transplant surgery) affected their lives. All interviews were conducted by a single investigator (L.E.) and tape-recorded and transcribed verbatim. Transcripts were immediately reviewed and tentative themes were highlighted. Interviewing and recruiting new participants continued until no new themes emerged from the data and the categories were saturated. Interviews lasted 25 to 60 minutes with the average interview lasting 45 minutes.

Sociodemographic data (eg, age, race, marital status, education, employment status, and income) and health history (eg, time since transplant, left ventricular ejection fraction, and New York Heart Association class) were obtained from patient self-reports and medical records.

Analysis

Descriptive statistics and measures of frequencies were used to characterize the study population. Correlations between meaning, life purpose, and psychological mood states (anxiety, depression, and hostility) were analyzed using Pearson product-moment correlation coefficients. The significance level was set a priori at $P \leq .05$.

Content analysis of linguistic data was used to identify common themes. Major concepts and thematic areas were identified as a result of an iterative process of interviewing, reading, coding, rereading, and recoding interviews. Coded data were clustered into related categories. The categories were examined for similarities and differences, and similar concepts were reduced to enhance generalizability. Credibility, which is determined by the perceptions of the persons who lived the experience, was established by continued and prolonged exposure of the investigators to the answers of the respondents. In

Table I

Demographic and clinical characteristics of elderly female heart transplant recipients (*n* = 33)

Characteristic	Mean ± SD	<i>n</i> (%)
Age, y, (mean ± SD)	62.3 ± 5.5	
Race, %		
White		23 (69.7%)
Black		4 (12.1%)
Other		6 (18.2%)
Employment Status, %		
Employed		4 (12.1%)
Unemployed/Retired		29 (87.9%)
Marital Status, %		
Married		19 (57.6%)
Not Married		14 (42.4%)
Education		
≤High School		16 (48.5%)
Vocational or Junior College		8 (24.2%)
≥ College		9 (27.3%)
Annual Income		
<15,000		17 (51.5%)
15,000–29,999		3 (9.1%)
30,000–49,999		6 (18.2%)
50,000–74,999		4 (12.1%)
≥75,000		3 (9.1%)
Number of years since transplant, (mean ± SD)	4.6 ± 4.8	
Ejection fraction	55.0 ± 5.5	
New York Heart Association (NYHA) Class		
NYHA Class I		23 (70%)
NYHA Class II		10 (30%)

addition, categories identified from the data were verified with the participants during their routine follow-up visits at the clinic, thus establishing credibility through corroboration. Colleagues and the research team addressed inter-rater reliability by reading the data and confirming that the emerging themes were representative of the raw information. This collaboration minimized tainting from personal biases and enhanced trustworthiness and rigor of the data.

RESULTS

Quantitative data

The sample consisted of 33 women who had their heart transplant surgery an average of 4.6 ± 4.8 years (range 1-22 years) before study participation. The demographic and clinical characteristics of women are summarized in Table I.

Table II provides the total scores on the variables of interest for women. Women reported moderate

Table II

Total meaning, life purpose, and psychological mood scores (*n* = 33)

Characteristic	Mean	SD	Range
Meaning ^a	30.64	8.32	10–49
Life Purpose ^a	40.12	13.78	17–63
Psychological Mood States ^b			
Anxiety	9.64	6.75	0–28
Depression	18.09	8.58	3–33
Hostility	8.55	5.64	2–24

^a = higher scores indicate higher levels of meaning and life purpose; ^b = higher scores for anxiety, depression, and hostility indicate higher levels of dysphoria

degrees of meaning and life purpose. In addition, we found that women had moderate to high levels

Table IIICorrelational matrix for the key variables ($n = 33$)

Variable	Meaning	Life Purpose	Anxiety	Depression	Hostility
1. Meaning	1.000				
2. Life Purpose	0.353*	1.000			
3. Anxiety	-0.395*	-.544†	1.000		
4. Depression	-0.474†	-.761†	.719†	1.000	
5. Hostility	-0.313	-.461†	.519†	.796†	1.000

* $P < .05$, † $P < .001$

of anxiety, depression, and hostility. The correlational matrix for the key variables is presented in Table III. We observed a correlation between women's sense of meaning and life purpose; higher meaning scores were associated with higher life purpose scores ($P < .05$). Meaning was also associated with feelings of anxiety ($P < .05$) and depression ($P < .001$), but not related to feelings of hostility. On the other hand, perceptions of life purpose were significantly correlated to all 3 mood states ($P < .001$); higher levels of life purpose was associated with lower dysphoria.

Qualitative data

Perceptions related to illness. Two major themes, fear and lack of control, emerged from the thematic analysis that explored women's perceptions (feelings) related to their heart disease and transplant surgery.

Fear. Women expressed their concerns of possibly dying in their sleep before the transplant surgery. They were worried that not enough hearts were available for everyone on the list. One woman shared her fear of not being strong enough to withstand the complications of her heart disease. Although fear for oneself was expressed by some of the women, a majority of the women described being more worried about their friends and families than themselves. During the wait for a donor heart, they wondered repeatedly how their spouses or children would accept their death. One woman stated:

It just scares me to think what [my husband] would do if something were to happen to me. . . he seemed to be ready to accept that I could have died waiting for a heart, but now things have changed and he seems so hopeful that things will be alright.

After the surgery, some women feared that their

health was going to be worse; some thought it was going to be better. Several of the women expressed concerns related to side effects of treatment (eg, weight gain, high blood pressure, and diabetes). The fear of rejection was a common thread in the lives of all the women. One woman who had gone through several changes in her immunosuppressive regimen feared that an effective treatment for her would not be found. Another woman explicitly conveyed her fear of rejection in the following statement:

Every time I was due for my annual biopsy, I would feel faint and scared. . . every year when I celebrated my second [transplant] birthday, I would detach myself from the world and hide in my closet until I knew that my angiogram was clear. . . then a new cycle would begin all over again.

Lack of control. All the women expressed that during moments of their illness and recovery from transplant surgery, they had perceptions of not having control over their health and their lives. This lack of control made some feel depressed; several women expressed anger. Several women who described feeling depressed shared that they tried not to show their emotional pain to others, but often it became unbearable to hide it. One woman described how the symptoms of heart failure affected her:

I looked half dead and I couldn't do anything. I huffed and puffed when I walked. I'd see other people having a good time and I'd want to go out and do it myself, but I couldn't. . . it was like forcing my body to believe that my mind was in charge, but no, it was all a cover up.

Another woman shared how frustrated she was when she couldn't control an event (in this case, a cardiac arrest) associated with her heart disease that influenced her family's happiness:

My son was going to get married, and I promised myself I would not spoil his big day, but with my luck my worse nightmare came true. . . I fainted right before the ceremonies began. . . I found out later that I had some irregular heart beats and almost died. . . it devastated my son and daughter-in-law and the rest of the family and I felt so down."

Motivating factors in recovery. Although the women in this study were often fearful and perceived themselves as powerless, they also described several motivating forces that facilitated recovery.

Optimism. Women described being optimistic during the worst times of their illness, which helped them maintain hope. For example, one woman stated:

I tried to be hopeful that my health would stabilize. . . that I'd make it through another day and beat all the odds.

The women also expressed optimism in their relationships with others. They shared that their confidence in the health care team helped sustain optimism. Several women described feeling grateful for the kindness and support that they received from the doctors and nurses at the clinic. One woman captured how she felt about the medical team in the following:

We always felt that they (doctors and nurses) were always smiling and encouraging us to be strong; they always treated us with respect and this really made a big difference. . . If they believed we were going to be okay, then we needed to believe it ourselves.

Faith. Several women in the study described turning to God when they first found out they were sick. One woman said:

I knew that God had a plan for me and I trusted His wisdom.

Another woman shared that her faith in a *Supreme Being* and in the medical team reassured her that things would work out for the best. Women revealed that after the surgery they turned to faith to help them through the restrictions and challenges associated with post-transplant adjustment. One woman described how talking with God and praying helped ease her burden:

I believed a lot in God and in the power of prayer. . . I felt very close to God. When I was too scared to talk with my family or friends, I talked to God. I wasn't afraid that He would react or get hurt. I brought my fears and aches and pain to Him, and I felt He was always there to make things easier for me.

Acceptance. Women in the sample spoke about illness as being an "ordeal" or a "storm that comes

and goes." They shared their near-death experiences before transplant surgery and reported feeling at that time that they had "come to accept the worse," if this was to be their fate. During recovery from transplant surgery, feelings of resignation and acceptance persisted. One woman who spent 1.5 months in the hospital after surgery because of transplant complications stated:

I felt like I was at peace with the world. . . I was given the chance [transplant surgery] to live again and for that I was thankful.

Some women indicated that they had not expected problems or complications after surgery, but when they realized that the recovery period required an equal share of adjustments, they willingly accepted their restrictions and limitations.

Altruism. During the period before transplant, many of the women described their attempts to bring a sense of normalcy to their lives by trying not to focus on or think too much about their heart failure or their need for surgery. Some described focusing on other activities. After surgery, several women expressed a desire to be strong for others. This altruism stemmed from their desire to "give back" what was given to them or a desire to "make a difference" in someone's life. One woman vowed to develop a support group for women requiring heart transplantation. She recounted her days before transplant and expressed:

Things would have been easier for me if I had someone to share my fears with. . . someone who was also going through what I was going through. . . Now that I am feeling better, I'd like to make that possible for others. . . I could even share my story with them.

Similarly another woman recalled her own experiences with supporting and getting support from another transplant woman:

I met another woman who lived close to me when I went to the clinic and we became really good friends; we'd come to the clinic together. I cried when she cried and we both shared our joys too. . . we encouraged each other to go for walks and to eat right. . . I got my heart transplant first and she was happy for me, and I was so glad when she got hers a few months later. . . I don't know how I could have made it without her!

Self-transcendence. All the women described coming across obstacles that hindered their recovery at some point after the surgery, but a majority expressed their pride in simply "making it through the storm." One woman, in sharing her experiences, said:

Sure, I still have my share of aches and pains and

I wake up some days feeling miserable, but what matters to me is that I rose above the occasion and made it through the surgery. . . that was ten years ago, and I would never give up the chance that I was given to re-live my life.

Similar phrases that were used to connote self-transcendence were “getting through,” “conquering the enemy,” “overcoming,” and “going beyond.” Many of the women said that their experiences helped them look beyond “worldly needs” and appreciate the “meaning” and “essence” of life. The following statement reflected self-transcendence:

Sure, we [(my family)] did not always have the health we wanted or the money we needed, but we didn't let that affect us. . . You just learn to accept what you can do and make adjustments for what you cannot do. . . I'm just happy to be alive. . . there are so many things that you are able to do and to experience when you have more life.

Self-fulfillment. Self-fulfillment was a concept that many women expressed after the transplant surgery. Words that participants used to convey a sense of self-fulfillment were “accomplished,” “achievement,” “success,” and “realization of goals.” One of the women described the experience as similar to running a race and making it to the finish line:

I ran what seems like miles and came across some rocky roads. . . I slipped and fell along the way, at times I was badly hurt, but what matters the most is making it to the finish line where everybody is cheering you on because you've fought the biggest race in life that you can ever run. . . the race against a deadly disease that wants to take your winning trophy.

Another woman described how overcoming each of the complications of her heart disease and transplant made her feel like she had triumphed over the enemy and won the battle:

In 1992, my doctors told me I had 4 to 6 months to live. . . I was young and was just finishing my nursing degree and at first I just wanted to give up, but there was just so many things I wanted to do in life so I tried to stay positive and every time I experienced a setback in my health I didn't let it get to the best of me. . . I got my heart transplant, which came with its share of challenges, but I have surpassed them all.

Changing life goals. Setting goals and targets was common for women during the period before transplant. These goals equated with things that the women felt they still needed to achieve in life. A majority of the goals focused on special occasions or family events including the birth of a grandchild, the graduation or marriage of a child, or, in 2 women, their golden anniversary. These life events became dreams that gave women the desire to live.

After the surgery or the “second chance at life,” as participants referred to it, the women created new goals or priorities in life. One woman clearly depicts how her goals and priorities changed after the surgery:

I used to always be one of those I, *me, myself* people but I would never have known or admitted it until I became sick. There had to be an incentive for everything I did and I always asked what was in it for me. But getting sick and being given a new heart has helped me realize that there is more to life than I, me, or myself. Now I focus on how I can be of help to others and how I can in simple ways return some of what was given to me when I got my new heart.

Several women also shared how taking responsibility for their health needed to be an important priority for them during their recovery. As one woman stated:

It is a marvelous gift to be able to get your life back again, but there is always a price. . . there is no such thing as a free lunch. One needs to take responsibility for his or her health and that begins with understanding what is expected of you in terms of medications, diet, and exercise. . . understanding inspired me to be the patient I needed to be and when I didn't understand, I had the doctors and nurses explain things to me.

DISCUSSION

Our findings support that women experience moderate levels of meaning and life purpose after heart transplant surgery. However, psychological distress (anxiety, depression, and hostility) was not uncommon in our sample. Similarly, earlier studies report on the high prevalence of psychological distress in the immediate recovery period¹ and several years after heart transplantation.^{4,15} Our findings validate previous data and support the presumption that heart transplantation is not a cure. Transplant patients actually trade one set of problems for another.¹⁰ High levels of psychological distress infer that after transplant patients live with continuing unpredictability and uncertainty. Patients face the fear of physiological rejection of the new heart and continuing possibility of death.

We also provide strong evidence for a clear relationship between meaning and life purpose and psychological distress. We found that our quantitative and qualitative data were mutually complimentary and provided us with additional information to support our assumptions that female transplant recipients experienced psychological distress before and after surgery. Our findings underscore the importance of developing a clearer understanding of

how women cope with the stressors of transplant surgery. Additional research on the role of meaning and purpose can make a valuable contribution to our understanding of the factors that influence life satisfaction among female heart transplant recipients.

Women expressed feelings of fear and lack of control over their lives in the pre and post-transplant phase of their illness trajectory. Although fear for oneself was commonly reported (eg, complications, rejection, or death), fear for how others would cope with any potential setbacks in their health and recovery was an overriding theme. Likewise, women shared how lack of control over their lives contributed to perceptions of poor life satisfaction. Women had to deal with the reality that they would never be totally "healthy" or "normal" again. It is likely that fear and lack of perceived control were antecedents of psychological distress in our sample. Since neither one of these concepts was captured in the standardized instruments, efforts to include an assessment of these variables in future research should be explored.

The use of a qualitative approach provided us with a clearer sense of how women, in particular, felt about this major life experience. Compared to other studies with samples including majorities of men, our findings indicate that women and men share some similar perceptions after heart transplant,^{6,16} particularly acceptance and optimism, changing life goals and priorities, self-transcendence, and faith. The finding that female transplant recipients report lack of control as a perception of their illness is unique and has not been reported by investigators who included men in their samples. It could be that men experience issues of control differently than women, or that men are less forthcoming in discussing experiences involving loss of control. Further study is needed to explore this issue.

Few data exist to allow evaluation of our qualitative findings in relation the experiences of recipients of other organ transplants. In the sole exploratory report of perceptions of quality of life after liver transplant (Robertson JAN), liver transplant recipients endorse not *feeling normal* after transplant and acknowledge optimism as a mediating factor in their recovery. Though these observations suggest that there are commonalities in the experiences of heart and liver transplant recipients, more data are needed to deepen and extend our understanding in this area.

Our qualitative data support that whereas women face major challenges related to their illness and heart transplant experience, a majority also

reported having positive attitudes toward the transplant surgery. Participants in a similar study reported several of the coping mechanisms described by women in our sample, including optimism, acceptance, faith, and altruism.⁶ Equating the application of these coping mechanisms with discovering meaning may be a logical explanation that mediates the relationship between meaning and psychological distress. Likewise, feelings of self-transcendence, self-fulfillment and the identification of changing life goals could compare with a realization of life purpose that may also directly or indirectly influence psychological distress.

In an earlier investigation, researchers revealed that transplant patients actually transitioned through several phases after surgery that they referred to as "phases of enduring illness."¹⁶ The authors describe the first 2 phases, *confronting the illness* and *reframing*, as mostly occurring in the pre-transplant period or in the immediate post-transplant period. Before transitioning to the last phase, *recovery*, patients go through *facing mortality*. Intuitively, we can infer that women in our sample who were transitioning between the latter 2 phases of illness were finding meaning and purpose that sustained their hope and helped them confront their illness. Although women experienced anger, depression, and hostility after transplant surgery, discovering meaning and purpose through self-reflection, knowing God, and relationships with others helped them cope with their experiences. This interpretation is supported by other findings in a previous study of pre-transplant patients.¹⁷ Patients coped with the pre-transplant evaluation experience by a process of self-reflection and self-transcendence.

Our quantitative data is limited by the small sample size and relative homogeneous sample, which limits generalizability of findings to other female heart transplant recipients. However, since the qualitative data provide additional data to compliment the quantitative data, we postulate that women continue to experience dysphoria after heart transplant surgery.

Our findings provide the initial groundwork for developing a theoretical model that will address the unique needs of female heart transplant recipients. Additional research is needed to explore other variables that could potentially influence the experiences of women after heart transplant surgery (eg, lifestyle changes, self-care behaviors, and compliance with medical regimens). Likewise, research that focuses on developing and testing interventions to help alleviate fear and increase perceived

control may be key to enhancing a sense of meaning and life purpose for this vulnerable population.

CONCLUSION

In summary, we found that despite the many challenges that women face both before and after heart transplant surgery, a majority of the participants were able to utilize coping strategies to help them regain control over their lives. Our findings support the need for clinicians to provide effective psychological counseling to women before and after transplant surgery that focuses on individual concerns and promotes positive meaning and optimistic coping behaviors. Facilitating dialogue about life's meaning and purpose in female heart transplant recipients may be key to minimizing psychological distress in this vulnerable population.

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