Self-care behavior, hope, and social support in Taiwanese patients awaiting heart transplantation

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Abstract

Objective: The purpose of this study was to examine the self-care behavior, hope, and social support in patients awaiting heart transplantation and to explore all the correlative and related factors.

Methods: In total, 45 participants who met the selection criteria were selected by purposive sampling from four medical centers in Taiwan. The three instruments Self-Care Behavior Scale, Herth Hope Index (HHI), and Social Support Inventory were used for data collection.

Results: Significant, positive correlations among self-care behavior, hope, and social support were observed. Social support was the best predictive factor for both self-care behavior and hope.

Conclusion: The outcomes of this study can help medical care personnel better understand the self-care behavior, hope, and social support in patients awaiting heart transplantation and can also serve as a reference when developing relevant interventions for these patients.

Keywords: Heart transplantation; Self-care behavior; Hope; Social support

Introduction

Heart transplantation has become one of the major treatments for end-stage heart failure patients [1]. Currently, in Taiwan, there are about a hundred patients waiting for heart transplantation. However, as people have just begun to embrace the idea of organ donations, there were only 4.1 organ donors out of one million people [2]. In 2000, there were only 93 organ donors, and only 41 patients benefited from heart transplantation opportunity [3]. The mortality rate among patients on the heart transplantation surgery waiting list increased from 10% in 1988 to 30% in 1996 [1].

Struck by the potential deterioration of symptoms during the waiting period, and feeling that their health condition is out of control, patients may feel scared, reduce their social activities, and even feel hopelessness [4]. The more hopeless a patient feels, the stronger intention they may have to commit suicide [5]. Roberts et al. [6] pointed out that, when patients feel hopeless, they lose their appetite, become weaker, and lose weight. Behavior wise, they tend to comply less with their medical treatments, feel sad and passive, and stop learning. Dressler [7] also pointed out that some patients feel regret when they know they are on the waiting list, with up to 51% of them having the intention of committing suicide. Johnson et al. [4] indicated that patients’ lack of hope could speed up the deterioration of their heart disease. Therefore, continuously giving patients hope during the waiting period is a potentially effective treatment policy [8].

Previous studies revealed that the higher social support patients had, the more hope they held [8,9]. Langford et al. [10] pointed out that the most available social support included providing individual emotional support, informational support, and appraisal support. Friedman’s study...
revealed that different types of support were required for different occasions [11]. Sometimes, general emotional support turned out to be more effective than any other types of support [12].

Having good self-care behavior can improve one’s quality of life and prolong one’s life span [13]. The major self-care behaviors for patients with end-stage heart failure included reducing dyspnea, avoiding laborious activities, taking proper rest, and reducing all discomforts resulting from the disease [14]. Ni et al. [15] indicated that the main reasons for rehospitalization for end-stage heart failure patients was that they lacked a knowledge of self-care. Forty percent of patients did not know the importance of monitoring weight on a daily basis, and 37% did not realize the warning sign of weight increase.

Social support is an important factor for helping patients maintain their health or recover from an illness [16]. For cardiac disease patients, social support can help them better comply with medical treatments [17]. Both social support and self-care behavior are key factors for helping patients restore their health [18]. Rudis et al. [19] demonstrated that a strong social support system can contribute to the survival of patients throughout the entire organ transplantation waiting process.

Among all the patients waiting for heart transplantation, only 24% stayed in the hospital and had their disease symptoms controlled with medical equipment, while almost 76% of patients simply stayed at home waiting for notification from the hospital [16]. However, there has been very limited research on how home patients should take care of themselves during the heart transplantation waiting time. The purposes of this study were to examine the self-care behavior, hope, and social support and their related factors among patients awaiting heart transplantation.

Methods

Design and participants

This is a descriptive and correlational study. Participants were selected based on the following criteria: aged over 18 years, conscious, communicable, willing to participate in this study, having been diagnosed as needing to receive a heart transplantation as necessary treatment, and having been on a waiting list. In total, 45 awaiting heart transplantation patients were selected within 6 months from the five major heart transplantation medical centers in Taiwan. They were all aged between 18 and 67 (average = 46.9 ± 15.5) years old, with an average of 9.7 (±4.3) years of educational background; the majority of participants were male (82.2%), with spouses (71.1%), jobless (64.4%), and financially supported by others (57.8%). The times waiting for heart transplantation surgery were between 30 and 1460 (average = 384) days. Among these patients, 64.4% were found to have more than one complication, mostly gout and diabetes; the frequency of being rehospitalized due to heart problems was from 0 to 10 times, mostly once or twice (60%). With regard to self-perceived health status, most (77.8%) patients considered themselves to be in passable condition.

Instruments

Apart from gathering background data on participants, including their age, gender, years of education, marital status, religion, financial resources, occupation, and physical illness status, such as days of waiting for heart transplantation, current complications, patient’s self-perceived health status, and frequency of being hospitalized due to heart problems during the waiting stage, in this study, we also required the patients to fill out the following three questionnaires.

1. Self-Care Behavior Scale. This scale was amended by researchers based on the self-care behavior scale developed for heart failure patients by Lin and Chao [20] and researchers’ clinical experiences of caring cardiac patients. There is a total of 20 items, including five subscales of self-monitoring, medicine intake behavior, diet control, activity performance, and preventative health care. The higher the score is, the better is the patient’s self-care behavior.

2. Herth Hope Index (Chinese version; HHI). The Chinese version of the HHI, translated by Chen and Wang [5], was adopted in this study. There are 12 items, including three subscales of inner sense of temporality, positive preparation and expectation, and interconnectedness with self and others. The higher the score is, the more hope patients have.

3. Social Support Inventory. The Social Support Inventory was developed by Tseng [21]. There are 15 items included in four subscales of emotional support, instrumental support, informational support, and appraisal support. The higher the score is, the better is the patient’s social support.

Based on data of the 45 participants, the internal consistency reliability Cronbach’s alpha readings for the three study tools were .82 for the Self-Care Behavior Scale, .74 for the HHI, and .88 for the Social Support Inventory. Next, 10 patients out of the total 45 participants that had stabilized conditions were selected to repeat the same tests 2 weeks later, and the data obtained from the two sets of tests significantly correlated with each other: the Self-Care Behavior Scale (r = .927, P < .0001), the HHI (r = .942, P < .0001), and the Social Support Inventory (r = .860, P = .001). These revealed good test–retest reliability with the three tools. The validity of the three tools was supported
by the Content Validity Index readings of .98 for the Self-Care Behavior Scale, .95 for the HHI, and .97 for the Social Support Inventory.

Data collection procedures

Patients were referred to the researcher by physicians. Patients who met the selection criteria were asked to participate in the study. Then, a home visit was arranged for a structured interview using the Self-Care Behavior Scale, the HHI, and the Social Support Inventory. A thorough explanation of the purpose and process of the study was provided by the investigator, and informed consent was obtained from each participant. During the entire data collection process, patients had to report all relevant complications, while the researchers could collect data, assess the participants’ blood pressure, heart rate, and dropsy status, discuss outcomes with the patients, and provide proper self-care information to them after the structured interview.

Data analysis

All data were analyzed with SPSS for Windows version 10.0 package Software. Means and standard deviations were used to display the descriptive statistical results; t test, one-factor ANOVA, Pearson’s correlation, and stepwise regression analysis were used to reveal the inferential results.

Results

The self-care behavior, hope, and social support in patients awaiting heart transplantation

Scores for self-care behavior had an average overall score of 60.09 ± 8.5 and an average score of 3.0 on each item; on the subscales, the average score for “activity performance” was the highest, while that for “self-monitoring” was the lowest (Table 1). As for the scoring of individual items of the Self-Care Behavior Scale, the top three highest scores were for “I obey the doctor’s prescription and take medicine on time”, “I follow the doctor’s instructions, and return to the hospital for follow-up treatments on time”, and “When I feel uncomfortable, I will go for a checkup and treatment at a qualified hospital with qualified doctors”; the top three lowest scores were for “I measure my weight every day and record it for my doctor’s reference”, “I measure my blood pressure everyday and watch for changes in my blood pressure”, and “When I do not understand the function of certain medicine I am taking, I will actively consult with medical care personnel about it”.

Scores for the HHI had an average overall score of 36.67 ± 3.75 and an average score of 3.05 for each item; on the subscales, the average score for “interconnectedness with self and others” was the highest, while that for “inner sense of temporality” was the lowest. As for the scoring of individual items, the top three highest scores were for “I feel a very powerful support inside me that makes me want to live”, “I can give and take love and care from others”, and “I am able to recall some happy moments of my past life”; the top three lowest scores were for “I have present and future plans of my life”, “My religion can give me sense of comfort and commitment”, and “I feel afraid of the future”.

Table 1
Means and standard deviations (S.D.) of self-care behavior, hope, and social support (N=45)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number of items</th>
<th>Range</th>
<th>Mean</th>
<th>S.D.</th>
<th>Mean for each item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-care Behavior Scale</td>
<td>20</td>
<td>20–80</td>
<td>60.09</td>
<td>8.5</td>
<td>3.00</td>
</tr>
<tr>
<td>Self-monitoring</td>
<td>6</td>
<td>6–24</td>
<td>17.09</td>
<td>3.10</td>
<td>2.84</td>
</tr>
<tr>
<td>Medicine intake behavior</td>
<td>3</td>
<td>3–12</td>
<td>9.24</td>
<td>1.49</td>
<td>3.08</td>
</tr>
<tr>
<td>Diet control</td>
<td>3</td>
<td>3–12</td>
<td>8.96</td>
<td>1.68</td>
<td>2.98</td>
</tr>
<tr>
<td>Activity performance</td>
<td>3</td>
<td>3–12</td>
<td>9.56</td>
<td>1.62</td>
<td>3.18</td>
</tr>
<tr>
<td>Preventative health care</td>
<td>5</td>
<td>5–20</td>
<td>15.24</td>
<td>2.84</td>
<td>3.04</td>
</tr>
<tr>
<td>Herth Hope Index</td>
<td>12</td>
<td>12–48</td>
<td>36.67</td>
<td>3.75</td>
<td>3.05</td>
</tr>
<tr>
<td>Inner sense of temporality</td>
<td>4</td>
<td>4–16</td>
<td>11.91</td>
<td>1.49</td>
<td>2.97</td>
</tr>
<tr>
<td>Positive preparation and expectations</td>
<td>4</td>
<td>4–16</td>
<td>12.24</td>
<td>1.63</td>
<td>3.06</td>
</tr>
<tr>
<td>Interconnectedness with self and others</td>
<td>4</td>
<td>4–16</td>
<td>12.51</td>
<td>1.55</td>
<td>3.12</td>
</tr>
<tr>
<td>Social Support Inventory</td>
<td>15</td>
<td>15–60</td>
<td>45.76</td>
<td>6.87</td>
<td>3.00</td>
</tr>
<tr>
<td>Emotional support</td>
<td>4</td>
<td>4–16</td>
<td>12.71</td>
<td>2.02</td>
<td>3.17</td>
</tr>
<tr>
<td>Appraisal support</td>
<td>3</td>
<td>3–12</td>
<td>8.93</td>
<td>1.40</td>
<td>2.97</td>
</tr>
<tr>
<td>Informational support</td>
<td>5</td>
<td>5–20</td>
<td>14.98</td>
<td>2.74</td>
<td>2.99</td>
</tr>
<tr>
<td>Instrumental support</td>
<td>3</td>
<td>3–12</td>
<td>9.13</td>
<td>1.89</td>
<td>3.04</td>
</tr>
</tbody>
</table>

Table 2
Social support resources for participants who have spouses and those without spouses (multiple choice) (N=45)

<table>
<thead>
<tr>
<th>Participants</th>
<th>Emotional support Spouses</th>
<th>Appraisal support Spouses</th>
<th>Informational support Spouses</th>
<th>Instrumental support Spouses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouses</td>
<td>No (n=13)</td>
<td>Yes (n=32)</td>
<td>No (n=13)</td>
<td>Yes (n=32)</td>
</tr>
<tr>
<td>Children</td>
<td>1(7.7)</td>
<td>13(40.6)</td>
<td>2(15.4)</td>
<td>12(37.5)</td>
</tr>
<tr>
<td>Parents or brothers</td>
<td>11(84.6)</td>
<td>6(18.8)</td>
<td>9(69.2)</td>
<td>7(21.9)</td>
</tr>
<tr>
<td>Friends</td>
<td>7(53.8)</td>
<td>8(25.0)</td>
<td>5(38.5)</td>
<td>6(18.8)</td>
</tr>
<tr>
<td>Health care personnel</td>
<td>0</td>
<td>1(3.1)</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Scores for the social support had an average overall score of 45.76±6.87 and an average score of 3.00 scores for each item; on the subscales, the average score for “emotional support” was the highest, while that for “appraisal support” was the lowest. The top three highest scores were for “Somebody cares about my health condition”, “Somebody will take care of me and my daily life while I am sick”, and “Somebody will provide me some guidance for my self-care daily life or substantially help me”; the top lowest scores were for “Somebody can provide me ways to release my pressure”, “Somebody can discuss with me about setting up my future goal for life”, and “Somebody can support my making decisions”. In addition, it was found that, for patients with spouses, their “emotional support”, “appraisal support”, and “instrumental support” mainly came from their spouses; for those spouseless participants, these types of support mainly came from their parents or siblings. And regardless of their having a spouse or not, their “informational support” mainly came from medical care personnel (Table 2).

Table 3 reveals that self-care behavior, hope, and social support were significantly correlated to each other. On the subscales, “appraisal support” was positively correlated to “self-care behavior”; “informational support” was positively correlated to “hope”; and “interconnectedness with self and others” was positively correlated to “social support”.

The correlation between self-care behavior, hope, social support, and participants’ characteristics and illness status

According to Table 4, those who had religious beliefs, occupations, and good feelings about their own health condition had a higher degree of hope than did those who did not. Although it seemed that the social support score did not significantly differ or was not affected by participants’ difference backgrounds with respect to the three subscales of social support, results revealed that female participants had significantly higher instrumental support than did the male participants (t=2.62, P<.05), and married participants had significantly higher emotional support than did the spouseless participants (t=−3.28, P<.01). With respect to the three subscales of self-care, married participants had better medicine intake behavior (t=−2.6, P<.05). The higher the educational background was, the better self-care behavior those participants had (r=.294, P<.05) and the more hope they held (r=.419, P<.01).

Predictive factors for self-care behavior and hope

The results of regression analyses conducted using participants’ overall scores for self-care behavior and hope as dependent variables, and their basic characteristics, illness status, hope, and social support as independent
variables, revealed that social support was the best predictor of self-care behavior and explained 29.4% of the variation in self-care behavior. Social support, educational background, self-perceived health condition level, religious beliefs, and marital status were all significant predictors for hope and totally explained 60.4% of the variation in hope (Table 5).

Discussion

This study reveals that most patients awaiting heart transplantation in Taiwan have to depend on others for financial support and that they are mostly jobless. This is similar to the results from the study of Porter et al. [22] that 80% of patients awaiting heart transplantation were unable to work, and Muirhead et al. [23] report that 61% were unable to afford their family’s living expenses. The time spent waiting for heart transplantation surgery in Taiwan was, on average, 384 days, which was obviously much longer than that in the United States at 300 days [1]. Hsu et al. [24] pointed out that the shortage of organ sources is the major restriction to successful heart transplantation in Taiwan. Dressler [7] found that, due to cultural differences, religious beliefs, governmental regulations, etc., only 10–20% of people were willing to become organ donors. In Taiwan, the accidental death rate has dropped 40% since 1997, when educational programs were launched and wearing a helmet while riding a motorcycle and fastening one’s seat belt while driving became mandatory [3]. In addition, Taiwanese people value the concept of a total corpse very much that they are reluctant to donate organs after death. All these factors, taken together, result in longer waiting periods for heart transplantation in Taiwan. Moreover, it was found

<table>
<thead>
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<th>Table 5</th>
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<tbody>
<tr>
<td>Stepwise regression analysis of self-care behavior and hope model indicators (N=45)</td>
</tr>
<tr>
<td>------------------------------------------</td>
</tr>
<tr>
<td><strong>Dependent variables</strong></td>
</tr>
<tr>
<td>------------------------------------------</td>
</tr>
<tr>
<td><strong>Self-care behavior</strong></td>
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<tr>
<td>------------------------------------------</td>
</tr>
<tr>
<td><strong>Hope</strong></td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>Self-perceived health status</td>
</tr>
<tr>
<td>Religion</td>
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<tr>
<td>Married status</td>
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</table>

* P < .0001.
that most patients tended to refuse heart transplantation surgery the first time they were informed. Crone and Wise [25] pointed out that about 41% of patients hesitated to undergo heart implantation surgery during the waiting period.

Regarding self-care behavior, the study revealed that most patients awaiting heart transplantation had good self-care behavior. Among all the self-care behaviors, self-monitoring was performed the least, especially the monitoring of blood pressure and weight. Ni et al. [15] reported that 40% of patients did not consider it necessary to measure their weight every day. In the meantime, Carlson et al. [26] also pointed out that 37.2% of patients were unaware of the hazard of a weight increase. Therefore, in addition to emphasizing the importance of taking medicine on time, health care personnel should also advise patients on the purposes and importance of self-monitoring.

As for the factors that affected the patients' self-care behavior, this study found that married patients had better medicine intake behavior than did those who were spouseless; this result is similar to the Stull et al. [17] report, which found that social support could enhance patient compliance with medical treatments. In addition, those researchers found that most patients enjoyed their spouses’ company at the hospital, and their spouses were able to understand the medical treatments given to the patients. Those patients who had poorer educational backgrounds had worse self-care behavior; this result is similar to those of previous studies by Wang et al. [18] and Rockwell and Riegel [27].

The outcome of this study revealed that the degree of hope of patients awaiting heart transplantation was higher than that of those of heart failure patients [9]. Most patients awaiting heart transplantation hoped that they would have a sound and healthy body, that their condition would not deteriorate, and that they would have the opportunity to undergo heart transplantation surgery; these are similar to the study outcomes obtained by Muirhead et al. [23], that 71% of awaiting heart transplantation patients expected to have healthy lives, and 78% hoped to live for at least another 5 years.

This study also revealed that those who had religious beliefs had more hope; this is similar to an outcome of previous studies by Gelling [28] and Fehring et al. [29]. The outcome of the study of Tseng [21] also revealed that 54% of patients considered religious beliefs to be a good source of spiritual comfort and a stabilizer of the emotions.

On top of that, those who had occupations had higher degrees of hope than did those who were unemployed, and those who had the same jobs as they did before becoming ill had even higher hope than did those who changed to easier jobs afterward. This is probably because, on average, those who were employed were in better physical condition than were those unemployed; they could have financial security from their salary, they could take care of their family, and they could obtain support from coworkers and feel positive about themselves. Those who were self-conscious about being in good health had more hope than did those who felt themselves to be in a passable or poor health condition. This result is identical to that from the study of Liu [30] that those in a poor health condition felt powerless to control their health. In addition, those who were financially viable had greater hope for their present and future lives than did those who had to depend on others for financial support; this is similar to the outcome of the study of Tseng [21], where those who were financially self-supporting or self-maintained had better self-confidence and better expectations about the future than did those who were financially supported by their family.

With respect to social support, patients awaiting heart transplantation reported the lowest score on appraisal support, revealing that participants did not receive enough compliments and encouragement from others. This is possibly because most participants were incapable of work (64.4%) and were financially supported by their family. Among all support sources, emotional support and appraisal support mainly came from spouses, while informational support mainly came from health care personnel; this result is similar to that of the study of Hirth and Stewart [8] on patients awaiting heart transplantation.

The spouse is the main social support source for a patient. This study found that married participants had better emotional support than did those who were spouseless, which is similar to the results reported by Lin [9] and Johnson [31]. Per the study on spouseless patients, those who were bereft of their spouses were found to have the lowest scores for evaluative and instrumental support. Friedman [11] conducted a study on heart failure patients and found that spouseless female participants had lower instrumental support than did those who had spouses. In addition, this study found that female participants obtained more instrumental support than males did; this result is similar to those of Lin [9] and Johnson [31]. In traditional Taiwanese society, men dominate the outside world, while women control domestic family affairs; men have greater dominance and determination over social position, work, and money than women do. As all female participants in this study were jobless, they felt themselves being granted more instrumental support than men are.

This study also reveals that social support is the best predictor for self-care behavior and hope. This is similar to the outcome reported by Wang et al. [18]. Lee and Wang [32] also found that family and relatives could best foresee variable factors in a patient's self-care behavior. When they obtained greater support and encouragement from the society, patients feel that it is important to take good care of their illness, and they feel empowered, with a strong will to carry out health care. The study of Lin [9] also found that social support is a good predictor of hope. The higher the social support that a patient obtained, the better degree of hope they had. Such being the case, by way of interaction with others, patients are reminded and encouraged, and positive feelings about their self-existence
are enhanced; they are then able to develop positive attitudes about things, to generate hope, or to be empowered with hope.

In conclusion, the findings of this study provided more information about social support, hope, and self-care behavior in patients awaiting heart transplantation, and it was found that social support was the best predictor for self-care behavior and hope.

**Limitations of the study**

Small sample size, purposive sampling, the absence of randomization, and the selection of participants from only five hospitals limited the generalization of the study findings. A self-report method rather than direct observation on self-care behavior may result in bias of measurements.

**References**


