Illness Representations and Self-Care Behaviors of Patients with Heart Failure

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Study Background

- Heart failure is a common terminal stage of various heart diseases and the incidence of heart failure is increasing worldwide.
- In the U.S., more than 5.1 million people have heart failure, 670,000 new cases per year for individuals 45 years or older (AHA, 2013).
- In Taiwan, heart disease is one of the top two leading causes of death, resulting in 17,121 deaths, representing 11.13% of all deaths in 2012 (Taiwan Ministry of Health and Welfare, 2013).

- Heart failure is one of the most common chronic diseases and long-tern adherence to therapeutic recommendations are required for favorable outcomes.
- Non-adherence to medical treatment among heart failure patients is high and results in frequent exacerbations and premature death.

- Patients create their own perceptions of their illness and its treatment in order to make sense of the respond to the illness (Leventhal et al., 2001).
- Understanding patients' illness perceptions may be a key to provide appropriate interventions, and may enable patients to manage their illness. However, they are rarely discussed during medical consultations.

Purposes of the Study

- To explore the illness representations and self-care behaviors among patients with heart failure
- To investigate the relationship between illness representations and self-care behaviors of patients
- To identify important factors related to self-care behaviors among patients heart failure

Definition of Terms (Leventhal et al., 2001)

- Illness Perceptions: are patients' beliefs about an illness and its treatment which comprised of three components: Identity, Causes, and Illness Representation
- Identity: is the illness label and perceived associated symptoms
- Causes: are factors or conditions believed to have caused the illness

- Illness Representations
- Timeline, the expected duration of the illness which may be short term or long term (timeline-acute/chronic) and/or cyclical or episodic (timeline- cyclical)
- Consequences, is the experienced consequences of the illness
- Control, the extent to which the illness can be controlled through personal behaviors (personal control) and/or treatment (treatment control)
- Illness coherence, is the individual's understanding of the illness
- Emotional representations, reflect affective reactions associated with the illness

Illness Perception ------ Coping Behaviors

Illness Identity

Illness Representation

- timeline acute/chronic
- time cyclical
- consequences
- personal control
- treatment control
- illness coherence
- emotional representation

Demographic Data

Self-care behaviors

- medication
- diet
- exercise
- symptom monitor
- regular follow-up

Study Framework

The Common-sense Model of illness cognitions and behavior (Leventhal et al., 2001) was adopted in this study

Cause

Methods

- Study design: A descriptive correlational research design
- Study participants: Patients who had been diagnosed of heart failure were recruited from outpatients of a medical center in Taiwan
- Inclusion criteria: (1) aged 20 years or older, (2) able to communicate, and (3) consent to participate in the study
- Exclusion criteria: Patients who had mental disorders, or severe comorbidities such as cancer, COPD, CRD, or liver disease with ascites

 Sample size estimation: for a multiple regression analysis with 10 predictors, an estimated sample size of 100 would be required

Measurements

Demographic data form including: age, gender, marital status, levels of education, NYHA classification, and duration of illness

Illness Perception Questionnaire-Revised (IPQ-R)

- Illness Representation Scale (38 items)
 - 1. Timeline acute/chronic (6)
 - 2. Time cyclical (4)
 - 3. Consequences (6)
 - 4. Personal control (6)
 - 5. Treatment control (5)
 - 6. Illness coherence (5)
 - 7. Emotional representations (6)

Scores range from 1 (strongly disagree) to 5 (strongly agree) for all of the 7 subscales

(Moss-Morris, 2002)

- High scores on Timeline-acute/chronic and Timelinecyclical indicate that beliefs about illness are more chronic and cyclical in nature.
- High scores on Controllability and Illness coherence indicate positive perceptions about controllability of illness and personal understanding of the illness condition
- Conversely, high scores on Consequence and
 Emotional representations demonstrate more negative outcomes and emotional reactions toward the illness
 (Moss-Morris, 2002)

- Cause Scale consists of 18 discrete reasons that may have caused the patient's heart failure
 - 1. Psychological attributions (6)
 - 2. Risk behaviors (5)
 - 3. *Immunity* (2)
 - 4. Cultural attributions (3)
 - 5. Balance (2)

Scores range from 1 (strongly disagree) to 5 (strongly agree). High scores for Causes reflect more perceived reasons for the illness

(Moss-Morris, 2002)

- The original <u>Identity Scale</u> of the IPQ-R was adapted for use in heart failure patients by modifying the question stems based on the "Perception of Heart Failure Symptom Inventory" (23 yes/no items).
 - 1. *Frailty* (7)
 - 2. Edema related symptoms (4)
 - *3. Circulation disturbance (5)*
 - 4. Pain (4)
 - 5. *Impaired daily life* (3)

Score ranged from 0 to 23 with higher scores indicating more symptoms, which are related to heart failure.

(Moss-Morris, 2002; Wang, 2003)

- Hear Failure Self-management Behavioral Inventory (20 items)
 - 1. Medication
 - 2. Diet modification
 - 3. Regular physical activity
 - 4. Symptom monitoring
 - 5. Regular follow-up

Score of each item ranges from 1 (never) to 4 (all the time), the higher the score represents the better self-care behavior performance of the patient.

(Wang, 2003)

Validity and Reliability of Measurements

 Cronbach's alphas for the IPQ-R subscale ranged from 0.76 to 0.94 in the current study

| Instrument | CVI | Cronbach's α |
|---|-----|--------------|
| Identity Scale | 88% | .81 |
| Illness Representation Scale | 86% | .87 |
| Cause Scale | 84% | .89 |
| Heart Failure Self-management Behavioral Inventory | 96% | .86 |

Data analysis

- One-way ANOVA
- Person correlations
- Hierarchical regression was used to examine the effects of the potential predictors of self-care behaviors

Result-1 Demographic characteristics of study participants (N=100)

| Variables | Mean \pm SD/ n (%) | Min | Max |
|----------------------------|----------------------|-----|-----|
| Age (years) | 64.7 ± 12.3 | 28 | 86 |
| Gender | | | |
| Male | 67 (67%) | | |
| Female | 33 (33%) | | |
| Marital status | | | |
| Married | 90 (90%) | | |
| Single/Widower | 5 (5%) | | |
| Educational level | | | |
| Elementary | 49 (49%) | | |
| Junior/Senior high | 39 (39%) | | |
| College or above | 12 (12%) | | |
| History of chronic disease | | | |
| No | 8 (8%) | | |
| Yes | 92 (92%) | | 20 |

Demographic characteristics of study participants (N=100)

| Variables | Mean \pm SD/ n (%) | Min | Max |
|-----------------------------|----------------------|-----|-----|
| Smoking | | | |
| No/quit | 81 (81%) | | |
| Yes | 19 (19%) | | |
| Duration of HF (years) | 5.37±5.5 | <1 | 28 |
| NYHA | | | |
| Class I | 35 (35%) | | |
| Class II | 51 (51%) | | |
| Class III & IV | 14 (14%) | | |
| Received instructions about | | | |
| Care of HF | | | |
| No | 31 (31%) | | |
| Yes | 69 (69%) | | |

Result-2 Mean scores of illness identity scale (N=100)

| Variables (items) | Mean ± SD | Min | Max |
|-----------------------|-----------------|-----|-----|
| Illness Identity (23) | 2.67 ± 3.03 | 0 | 13 |
| Frailty (7) | $.74 \pm 1.16$ | | |
| Edema (4) | $.71 \pm .89$ | | |
| Circulatory (5) | $.31 \pm .63$ | | |
| Pain (4) | $.78 \pm .96$ | | |
| Daily Life (3) | $.13 \pm .39$ | | |

Scores of each item range between o and 1

Result-3 Mean scores of illness representation scale (N=100)

| Variables (items) | Mean ± SD |
|------------------------------|----------------|
| Illness Representation (38) | |
| Timeline acute/chronic (6) | $3.45 \pm .59$ |
| Time cyclical (4) | $2.76 \pm .69$ |
| Consequences (6) | $2.70 \pm .40$ |
| Personal control (6) | $3.61 \pm .59$ |
| Treatment control (5) | $3.57 \pm .48$ |
| Illness coherence (5) | $3.08 \pm .75$ |
| Emotional representation (6) | $2.48 \pm .78$ |

Scores for each item range from 1 to 5

Result-4 Mean scores of cause scale (N=100)

| Variables (item) | Mean ± SD | Min | Max |
|----------------------------|------------------|------|------|
| Cause (18) | 63.80 ± 17.1 | 18.0 | 84.8 |
| Psychological elements (6) | $2.56 \pm .82$ | | |
| Risk behaviors (5) | $2.74 \pm .81$ | | |
| Immunity (2) | 2.78 ± 1.12 | | |
| Cultural attribution (3) | $2.01 \pm .91$ | | |
| Balance (2) | $2.70 \pm .87$ | | |

Scores for each item range from 1 to 5

Relationship between demographic factors and Illness perception

- Timeline acute/chronic and personal control were associated with age (*r*=0.34, *p*<0.001; *r*=0.28, *p*<0.05)
- Illness coherence is positively correlated with education levels (p=0.009)
- Timeline scores are associated with NYHA classification (p=0.002)

Result-5 Self-care behaviors of study participants(N=100)

| Variables (item) | Mean ± SD | Min | Max |
|--------------------------|----------------|------|------|
| Self-care behaviors (20) | 63.7±8.73 | 40.0 | 80.0 |
| Medication | 3.70±.41 | | |
| Diet | 3.07±.71 | | |
| Physical activity | $2.87 \pm .89$ | | |
| Symptom monitor | 2.41±.49 | | |
| Regular follow-up | 3.90±.29 | | |

Scores for each item range from 1 to 4

Correlations between illness perception and self-care behavior

| V/ a mi a la l a a | Self-care behaviors | | | | |
|--------------------------|---------------------|-------|--|--|--|
| Variables | r | p | | | |
| Illness Identity | 02 | .421 | | | |
| Illness Representation | | | | | |
| timeline acute/chronic | 0.9 | 1.94 | | | |
| time cyclical | 01 | .488 | | | |
| consequences | 04 | .361 | | | |
| personal control | .45* | <.001 | | | |
| treatment control | .35* | <.001 | | | |
| illness coherence | .28* | .003 | | | |
| emotional representation | 20* | .022 | | | |
| Cause | - 17 | .048 | | | |

Result-6 Significant predictors of self-care behaviors (N=100)

| result o significant predictors of sent cure bendviors (14-100) | | | | | | |
|---|--------------|------|----------------------|------|----------------------|--------|
| In donon don to :: -1-1 | Mod | 1011 | Model 2 | | Model 3 | |
| Independent variabl | b | SE | b | SE | b | SE |
| Gender | 11 | .10 | | | | |
| NYHA classificatio | n05 | .07 | | | | |
| Educational levels | .03 | .07 | | | | |
| Illness Identity | | | | | | |
| Frailty | 045 | .057 | 033 | .053 | 029 | .054 |
| Edema | .024 | .064 | 033 | .059 | 043 | .062 |
| Circulatory Disturbance | .047 | .087 | .057 | .079 | .052 | .084 |
| Pain | 006 | .059 | 045 | .055 | 032 | .057 |
| Daily Life | .028 | .125 | .089 | .115 | .096 | .119 |
| | F=.196 | | F=4.38 | 9* | F=.660 | |
| | $R^2 = .010$ |) / | $R^2 = .27$ | 1 | $R^2 = .299$ | 9 |
| | | | $\triangle R^2 = .2$ | 169 | $\triangle R^2 = .2$ | 152 28 |

Significant predictors of self-care behaviors (N=100)

| Independent variable | Model 1 | | Mod | lel 2 | Mod | lel 3 |
|--------------------------|-----------------------|----|---------------------------------|-------|--|-------|
| Illness Representation | b | SE | / b | SE | b | SE |
| Timeline acute/chronic | | | 058 | .085 | 020 | .094 |
| Time cyclical | | | .105 | .073 | .087 | .078 |
| Consequences | | | .057 | .105 | .031 | .111 |
| Personal control | | | .286* | .120 | .310* | .131 |
| Treatment control | | | .073 | .135 | .073 | .140 |
| Illness coherence | | | .096 | .062 | .096 | .065 |
| Emotional representation | | | 064 | .060 | 086 | .063 |
| | F=.196 R^2 =.010 | | $F=4.38$ $R^{2}=.27$ $R^{2}=.1$ | l / | F=.660 R^2 =.299 $\triangle R^2$ =.1 | |

Significant predictors of self-care behaviors (N=100)

| Independent variable | Mod | Model 1 Model 2 | | Model 1 Model 2 Mo | | Mod | Iodel 3 | |
|------------------------|-------------------------------|-----------------|---|--------------------|---|------|---------|--|
| Cause | b | SE | b | SE | / b | SE | | |
| Psychological elements | | | | | .023 | .080 | | |
| Risk behaviors | | | | | 100 | .070 | | |
| Immunity | | | | | 033 | .048 | | |
| Cultural attributions | | | | | .057 | .066 | | |
| Balancing elements | | | | | .072 | .077 | | |
| | F=.196 R ² =.01 | | $F=4.389$ $R^2=.271$ $\triangle R^2=.1$ | | $F=.660$ $R^{2}=.299$ $\triangle R^{2}=.15$ | 52 | | |

Summary of Study Results

- In general, the patients perceived heart failure as a chronic condition but could be controlled by personal behaviors and/or treatment.
- Patients who perceived more causes of illness performed less self-care behaviors.
- Scores of illness identity were not significantly correlated to self-care behaviors

Summary of Study Results

- Except for timeline and consequences, significant associations were found between the rest of the illness representation scores and self-care behaviors.
- No demographic or clinical factors predicted selfcare behaviors in patients with heart failure.
- Personal control was the only significant predictor of self-care behavior, accounted for 27% of the variance in self-care behavior.

Conclusions and Suggestions

- Patients in our study believed that they had high levels of personal control, which suggests that they are more likely to take appropriate self-care behaviors.
- In our study, only personal control significantly predicts self-care behaviors. However, there are other factors that may affect self-care of the patients, such as self-efficacy, which may be considered and included in future study.

Conclusions and Suggestions

■ It would be important for health care providers to provide interventions for patients reinforcing their perception of controllability over the illness, enhancing illness coherence, clarifying misconceptions about causation, and relieving negative emotion as well, in order to facilitate self-care behaviors.

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Thank you