Experience on CHF self-management among patients with Chronic Heart Failure and their caregivers: preliminary observations and potential clinical applications

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Abstract

Patients with Chronic Heart Failure (CHF) and their family caregivers have to encounter a chronic progressive disease that produces extraordinary disruptions to their life situations over the course of CHF.

To explore the living experience of patient-caregiver dyads on self-managing CHF , the first author was attached to nurses at a cardiac ward for a clinical update during November 23-29, 2020. This paper narratively summarized the author's clinical observation log regarding the experience on CHF self-management among these four patient-caregiver dyads.

Three themes emerged :1) Emotional reactions over the course of CHF;2)Negative emotions resist self-management behavior; 3) Cognitive fusion impaired dyadic competence in making self-management decisions; 4) Relationship functioning influenced patients' and caregivers' contribution to patients' CHF self- management.

Dyadic approaches facilitating patients and family caregivers to deal with these struggles and find ways to move forward valued-based action is recommended.

Background

Chronic heart failure (CHF) is an endpoint of many cardiovascular diseases with escalating prevalence and incidence worldwide due to a dramatic increase in the aging population (1).

CHF is a debilitating disease that causes the impaired quality of life, significant morbidity, and frequent readmissions to hospitals among adults, especially the elders (2).

CHF self-management (E.g., self-monitoring symptoms, managing medications, restricting fluid and salt, maintaining regular physical activity, and seeking timely care(3)) is a conjoint venture to patients with CHF and their caregivers.

With the research focus on chronic illness self-management shifting from the individual patients to the patient-caregiver dyadic level, there is a need to explore their living experiences when self-managing CHF.

Methods

The first author was attached to nurses at a cardiac ward of the tertiary hospital in Hubei province, mainland China, for a clinical update during November 23-29, 2020.

During the period, she took the role of an observer with no clinical duty involved. She met four patient-caregiver dyads readmitted due to CHF problems of patients in that hospital and capture interactive opinions on CHF self-management from the perspective of patients and their family caregivers accompanying CHF.

This paper narratively summarized the author's clinical observation log regarding the experience on CHF self-management among the four patient-caregiver dyads.

Figure 1. One cardiac ward in the hospital.

Results

Table 1. Characteristics of four patient-caregiver dyads

Family	Gender of patient with CHF	Age(years)	Education level	Severity of CHF	Length of disease (years)	Caregiver
1	Male	81	High school	NYHA Class III	7	Wife
2	Male	64	Middle school	NYHA Class III	1	Wife
3	Male	74	Middle school	NYHF Class II	3	Daughter
4	Female	68	Primary school	NYHF Class III	5	Daughter

NOTE: CHF: chronic heart failure ; NYHA: New York Heart Association ; NYHA Class II: Slight limitation on physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitations, or dyspnea. NYHA Class III: Marked limitation on physical activity. Comfortable at rest but less than ordinary activity results in fatigue, palpitation, or dyspnea.

Table 2. Themes and sub-themes

Themes	Subthemes
1. Emotional reactions over the course of CHF for patients and caregivers	1) Patients: fear, helplessness, hopelessness, anxiety, anger, depression, feeling of being punished or being a loser or being burdensome
	2) Caregivers: fear, self-blame, guilt, anger, feeling of being out of control or being useless
2. Negative emotions resist self-management behavior	1) Limit patients' physical activities due to excessively fearing deteriorating symptoms and personal safety among patients and their caregivers
	2) Intermittent compliance with the diet was a method of coping with the boredom of low-salt food for patients momentarily, resulting in long-term non-adherence to salt restriction.
	3) Deliberately sudden stop some medicines which might produce embarrassing side effects (such as the urgency and frequency of urination) when socializing
	4) Continue to smoke cigarettes or drink alcohol when feel frustrated in response to perceiving a deteriorating functional status for the patients
	5) Become virtually housebound because of fear of sudden deterioration or a future loss, lose insight of personal life directions.
3. Cognitive fusion impaired dyadic competence in making self-management decisions	1) Experiential knowledge on water drinking and a low-sodium diet
	2) Deny the nature of the chronic progressive condition of CHF
	3) Stuck with the verbalization of Chronic heart **failure**
4. Relationship functioning influenced patients' and caregivers' contribution to patients' CHF self- management	1) Incongruence, or lack of communication
	2) Overreaction

Discussion

Patients and their family caregivers share in patients' emotional and cognitive experience in self-managing CHF.

Adverse emotion reactions in patient-caregiver dyads interplay a significant role in shaping patients' motivation and adherence to recommended self-management behavior.

Patient-caregiver dyadic experiential cognitive fusion strongly influence patients' self-management

Individual's relationship functioning can affect patient-caregiver dyadic incorporation on CHF management .

Conclusions

Emotional, cognitive, and relational struggles among patients and their caregivers represent significant factors in promoting adherence to CHF self-management and deteriorating functional status for the patients with CHF.

The findings provide preliminary evidence for future research to inform empirical studies, the development of patient-caregiver dyadic interventions and supportive family-based services.

Implications

Patients and their family caregivers need timely support to manage and adjust CHF.

Dyadic approaches facilitating patients and family caregivers to deal with these struggles and find ways to move forward valued-based action for both patients and caregivers is recommended.

Behavioral interventions (e.g., acceptance and commitment therapy) that focus on psychological flexibility development to facilitate an individual's acceptance of negative inner experiences and reconnect to meaningful life directions actively(4) should be further studied.

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