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Role of the Lebanese family caregivers in cardiac self-care: a collective approach

Nuhad Y Dumit, PhD,

Assistant Professor, Undergraduate Convener and Coordinator of Continuing Education, School of Nursing, American University of Beirut, Beirut, Lebanon

Sarah Abboud, PhD, RN,

Postdoctoral Fellow, Centers for Global Women's Health and Health Equity Research, University of Pennsylvania School of Nursing, Philadelphia, PA, USA

Angela Massouh, MSN, and

Clinical Instructor, School of Nursing, American University of Beirut, Beirut, Lebanon

Joan K Magilvy, PhD, FAAN

Professor Emerita, University of Colorado Denver College of Nursing, Aurora, CO, USA

Abstract

Aims and objectives—The purpose of this study was to explore perceptions of cardiac self-care among Lebanese family caregivers of cardiac patients. The specific aims were to describe the cultural context of cardiac care-giving in Lebanon and to explore the roles of family caregivers in enhancing self-care practices in patients with cardiac diseases.

Background—The role of family caregivers in Lebanon, a country in the Middle East, is assumed to extend beyond care-giving to making decisions on behalf of the patient and assuming responsibility for patient care. To date, there has been no study done to empirically validate this impression.

Design—The design of the study is qualitative descriptive that used semi-structured individual interviews with family caregivers of Lebanese cardiac patients.

Method—Thirteen family caregivers of cardiac patients were recruited from a referral medical centre in Lebanon. The participants were designated by their patients and interviewed in a place of their choice.

Results—One overarching and three themes emerged from data analysis describing roles of family care givers in cardiac self-care. The overarching theme was: Family caregivers of Lebanese cardiac patients were unfamiliar with the term, concept and meaning of Self-Care. The moral and emotional duty to care for the family member stemmed from obligation and responsibility towards patients (theme I). Interdependent care (theme II) between cardiac patients and their families

Correspondence: Nuhad Y Dumit, Assistant Professor, Convener and Coordinator of Continuing Education, American University of Beirut School of Nursing, Riad El Solh 1107 2020, Beirut, Lebanon. Telephone: 009613982873. ny00@aub.edu.lb.

Contributions

Study design: NYD, JKM; Data collection and analysis: NYD, SA; Manuscript preparation: NYD, SA, AM, JKM.

emerged as a significant cultural role. Family members play multiple supportive roles in care-giving namely emotional, informational and instrumental role (theme III).

Conclusion—In this study, family caregiver role is shown to be based in the sense of obligation and duty towards the sick family member who collectively provide different types of supportive care.

Relevance to clinical practice—Nurses have to give significant importance to the family caregiver role as an integral part of any culturally sensitive patient/family intervention.

Keywords

collective care; emotional role; family caregiver's role; family obligation; informational role; instrumental role; interdependent self-care; self-care perception; supportive role

Introduction

Cardiovascular diseases remain the leading cause of death worldwide, and in the current environment, the magnitude of this increase in incidence and prevalence has potentially major complications for the developed and more so the developing world (Gersh *et al.* 2010). After the age of 40, the lifetime risk of developing cardiovascular diseases is 49% for men and 32% for women (Lloyd-Jones *et al.* 2010). Approximately 80% of the 16.7 million deaths due to cardiovascular disease occur in low- and middle-income countries (Lopez *et al.* 2006). Deaths from noncommunicable diseases for all age groups and both genders constitute 85% of the total deaths in Lebanon, 47% of which are attributed to cardiovascular diseases (World Health Organization 2014).

Individuals with cardiovascular diseases are routinely coached to actively engage in self-care behaviours; besides, education aimed at promoting these behaviours is integrated into all major cardiovascular disease clinical practice guidelines (Fihn *et al.* 2012). As such, self-care is a central concern for nursing and a nursing research priority for over a decade (Dickson *et al.* 2013). In 2009, the American Heart Association published a scientific statement on the importance of self-care in the management of heart failure; this has been echoed in the 2013 guidelines from the interdisciplinary American College of Cardiology Foundation/American Heart Association Task Force (Dickson *et al.* 2013).

Orem (1995) defined self-care as a dynamic process or an action system evidenced when individuals engage in actions to take care for themselves; she asserted that self-care is a learned behaviour characterised by deliberate action. In her editorial, Leininger (1992) maintained that Orem's definition of self-care focuses on the 'individual' which may be a counter to cultural beliefs, values and norms of some non-western cultures. Nevertheless, Godfrey *et al.* (2011) in their study of analysing 139 definitions of self-care concluded that the definitions are extensive and evolving and recommended comprehensive and encompassing definitions to include as many aspects of the concept as possible. In their discussion of their study results, though Godfrey *et al.* (2011) mentioned the many facets of self-care they were still short of addressing the concept from a collective/interdependent – as opposed to individual – perspective.

The transfer of care from inpatient to outpatient setting has shifted the responsibility of care of chronically ill patients onto the patients themselves as well as their caregivers (Wilkinson & Lynn 2005). Consequently, cardiac patients are encouraged, more so, expected to assume responsibility for their self-care, learn how best to live with heart disease and how to integrate behavioural modification and lifestyle changes to manage their health (Institute of Medicine 2002). This expectation is pre suming individual responsibility of patients towards self-care; however, this assumption may not be true in cultures where care is collective rather than individual (Leininger 1992, Dumit *et al.* 2015).

Background

Family caregivers play a major – and perhaps the most important – role in supporting older adults during hospitalisation and especially after discharge. Despite the growing evidence that affirms the role of family caregivers in helping the persons with chronic illness plan their care (Dunbar *et al.* 2008), research on the role of caregivers in enhancing cardiac self-care practices is meagre (Molloy *et al.* 2005, Dunbar *et al.* 2008).

Literature is in consensus that the lack of social support is associated with increased cardiovascular risk in patients (Smith & Ruiz 2002). Kärner *et al.* (2004) ascertained the effect of the family's response to illness, patient's well-being and, eventually, recovery from a cardiac event. Most of the literature addressing the caregiver role in cardiac illness relate to heart failure. Effective self-care is a fundamental outcome in the management of heart failure specifically in the context of outpatient care (Evangelista & Shinnick 2008). The Heart Failure Society of America mandates that to improve survival, enhance quality of life and reduce costly hospitalisations, patients with heart failure must adhere to complex medication, dietary and self-care regimens; adherence that often requires the assistance of the patients' family caregivers (HFSA 2006). Positive social support, provided by family caregivers, is linked to better self-care (Sayers *et al.* 2008), fewer heart failure hospitalisations, decreased risk of mortality (Mookadam & Arthur 2004) and better treatment adherence (DiMatteo 2004). On the other hand, lack of emotional support and living alone is related to the psychosocial distress in patients with heart failure (Scherer *et al.* 2007).

Cognizant of the fact that self-care is influenced by the culture, health literacy and health care systems (Moser *et al.* 2012), it is, thus, imperative to address the cultural dimension when exploring problems around self-care of patients with cardiac disease in a developing country like Lebanon. The emphasis on self-care in western communities comes from a cultural perspective that upholds patient independent self-responsibility (Moser *et al.* 2012). In contrast, the emphasis in other cultures, including Lebanon and the Middle East, is on family interdependence or collectivism. In Lebanon, the family is perceived as the cornerstone of the society whereby kinship ties play a significant and active role in the health care of any family member. Deyirmenjian *et al.* (2006) described Lebanese patients undergoing open-heart surgeries as passive-recipients of care where family members assume the role of care-giving and more importantly of making decisions on behalf of the patient. Kim and Flaskerud (2008) described the traditional values dominant in several Asian countries where the head of the household, usually the father, husband or son, is responsible

for making decisions on behalf of the patient. They maintained that in such cultures patients yield to the wishes of the family that acts as the protector to the extent that patient autonomy is disregarded when disclosing, diagnosis and deciding on treatments; the family has the final word (Kim & Flaskerud 2008).

In Lebanon, the family role in hospital care is very atypical. Close relatives attend to the patients during admission and all through hospitalisation to alleviate the patients' fears and worries and sometimes answer questions on their behalf (Adib & Mikkey 2003). Family members assume that 'patients prefer not to know...they become more anxious when they know' (Deyirmenjian *et al.* 2006, p. 112). The Lebanese family tend to make decisions on behalf of their patient in relation to disclosing information to the patient or making choices for therapy especially in cases such as heart disease or cancer. However, having a male-dominant health care system, the patient-doctor relationships are paternalistic; the final decision regarding disclosing the diagnosis and deciding on the treatment remains in the hands of the physician (Adib & Mikkey 2003). The patients, having unclear expectations of their disease process, tend to become dependent on the family for their care during and after hospitalisation and assume a sick role even though they could be recovering. The Lebanese family is typically over protective of the patient in a sense that family members exchange turns in providing care even when patient is hospitalised (Deyirmenjian *et al.* 2006, Gebara & Tashjian 2006, Dumit 2008).

Lebanese culture is family oriented, whereby family members not only support each other in all aspects of life including health care, but they are also required to preserve family values and integrity (Gebara & Tashjian 2006). End-of-life practices in Lebanon emphasise the importance of family involvement in patient care and the need to 'make the family one of the central elements in the communication protocol.' (Gebara & Tashjian 2006, p. 386). However, these family oriented cultural values may adversely affect achieving self-care outcomes as this process entails active engagement in self-care behaviours and assumption of self-care responsibility. Hence, a need exists to understand the perceptions of Lebanese family members of self-care, the ascribed meaning, and the role each plays in achieving care outcomes such as patient adherence to self-care behaviours for the prevention of disease complications.

The purpose of this study was to explore perceptions of cardiac self-care among Lebanese family caregivers of cardiac patients. The specific aims were to describe the cultural context of cardiac caregiving in Lebanon and to explore the roles of family caregivers in enhancing self-care practices in patients with cardiac diseases.

Methods

Design

The study was a qualitative descriptive research that used semi-structured individual interviews with a sample of family caregivers of Lebanese patients with cardiac diseases with an aim of gaining an in-depth understanding of the role of family caregivers in patient self-care in the Lebanese context. Qualitative descriptive studies are the design of choice when straightforward description of a phenomenon of interest is sought (Sandelowski 2000).

Data collection

Sample and setting—Thirteen family caregivers of cardiac patients were recruited from a tertiary referral medical centre's private clinics as well as ambulatory and outpatient departments; the cardiac patients of these family caregivers were diagnosed with coronary artery disease for more than one year. The inclusion criterion for caregivers was that s/he was designated by the patient as the caregiver to be interviewed. All caregivers lived with their patients. Contact with the caregivers was made after getting their approval through their patients; caregiver interviews were held in their homes. Participants were interviewed after signing the consent.

Procedure—Data were generated through semi-structured digitally audio-recorded individual interviews to allow participants to express their perceptions of their roles in cardiac self-care freely and in their own words. Participants consented to the interview and to the digital recording. The interviews took place in the participants' homes upon their request. The study's principal investigator (ND) conducted all the interviews, these lasted 40–60 minutes. Despite reaching data saturation by the eighth interview, the investigator continued the interviews to include participants from different geographic areas and religions. The four questions for the interview were open-ended, constructed by the researcher and evaluated for cultural congruence by three experts familiar with the culture. The four questions were: (1) I understand your family member (name) has a heart problem; what does that mean to you? (2) Have you heard of self-care? Tell me what you know about it. (3) How does (name) take care of her/himself? (4) What is your role? Tell me about what you do to help. The questions were translated into Arabic and back translated into English by an independent person blinded to the original English form. Back translation was done based on the seven-step guidelines recommended for cross-cultural health care research as maintained by Sousa and Rojjanasrirat (2011). The study was approved by the Institutional Review Board of the medical centre.

Immediately after the interviews, field notes and audio-recorded interviews in the Arabic language were transcribed. Then patterns were extracted and translated into English by the researcher using word processing software. Back translation of patterns was done by a nurse who was blinded to the original transcripts and fluent in the two languages.

Data analysis

Qualitative descriptive analysis was used to summarise the informational content of the data using data-driven codes and discovering patterns, categories and themes (Sandelowski 2000) pertaining to the role of family caregivers in cardiac self-care. Trustworthiness was enhanced through immersion in the data prior to the analysis making sure the findings reflected the meanings as expressed by the participants. The process of member checking was also used to obtain feedback from participants regarding the findings and their interpretation.

Results

The family caregiver participants, designated by their patients were primarily females (10), either the spouse (six wives and two husbands) or the daughters of the patients (4); only one son participated. Caregiver ages ranged between 33–82 years with a mean age of 46.5 years; none of the children caregivers were married. Three of the caregivers were able to read and write; four had completed middle school and six had a high school diploma. They all lived with their cardiac relatives. While not all of the housewives had jobs, three daughters worked as beauticians, and one as shop assistant. One husband was retired, the other worked in a company; while the son was a mechanic. A description of the demographic data of family caregivers is included in Table 1. The six families of the wives had dependent children who were at schools or colleges and depended on their fathers [the cardiac patients] who are the sole breadwinners of the family for their educational and daily expenses.

The analysis yielded one overarching theme and three main themes (Table 2). The next paragraphs include descriptions of the findings and quotes from the interviews. To protect participant privacy, names or pseudo-names are not used in the descriptions of the themes and quotes from the interviews.

The overarching theme identified was: *Family caregivers of Lebanese cardiac patients were unfamiliar with the term, concept, and meaning of Self-Care*. At first query, most of the participants (seven) had no recognition of the term ‘self-care’ (in Arabic ‘*Inaya Bilnafes*’ (العناية بالنفس)) and reported that they were not familiar with the term confusing it with psychological well-being because of the close pronunciation of the terms ‘self’ and ‘psyche’ in Arabic. When asked what such a term might mean, their responses varied. A noteworthy response was provided by several participants: ‘It means you should take more care of the sick person from the heart. Maybe you give more affection/emotions; you take care of him more. It could be that the heart should be more compassionate, to give more...’, ‘it might be care from a psychological manner’, ‘it is how a person can accept his problem psychologically, or be prepared for it’.

Theme I

The first theme was *obligation and responsibility towards patients* which included two subthemes: Moral and emotional obligation to take care of the other person even if he/ she can take care of himself/herself; and shift of responsibility. All family caregivers displayed a *sense of obligation* to be close to their patients and to take care of them even if the patients were able to take care of themselves. A 33-year-old male participant who takes care of his mother responded that: ‘She takes care of herself 70% correctly. She likes to take care of herself but we don’t let her get tired’; the participant continued ‘We have to be by her side... I should be near her...I go to the doctor just to be reassured’. An interesting response was by the daughter of one of the patients: ‘Even without being sick, parents should be taken care of by their children especially when they are getting old; we have to keep an eye on them, it’s even more when they are sick having had an operation’.

When asked about their role in the care, participants verbalised a *shift in responsibility*. One participant, a 50-year-old wife, of a patient stated:

I felt a lot of responsibility; I had to organize my time between the hospital, the work that he used to do in the morning, the kids and their school... When he returned to his work, the responsibility decreased but you still have to make sure that he doesn't get tired

Similarly a 47-year-old wife expressed the shift in responsibility by voicing out:

I said to myself what must I do? Kids are at university, how can we continue? ... Of course I felt it was a big responsibility... it is difficult. And at the end, he is 'the man of the house

A typical Lebanese traditional response was expressed by the 33-year-old son: 'I am responsible for her of course, and this is only a part, no matter how much I help my mother, it is never enough'.

Theme II

The second theme was: *interdependent care as a cultural role*. The majority of the family caregivers confirmed that their role and the role of the patients in the care management are interdependent. This was evident through the descriptions of the participants on how all family members have different but interrelated roles to play in taking care of the sick person. The wife of one of the patients, a 45-year-old participant expressed her role by saying:

...my role as his wife is to try to help him, to make his life easier. If I feel that he is not feeling well, I immediately tell him to go and rest. I help him with his food, for every doctor's visit or blood test, he tells me to go with him. I go, I don't hesitate. One has to learn these things obligatory to be able to help the sick

Another participant, a 42-year-old wife stated: 'I know each medication for what, and what dose he doesn't need me to remind him of his medications, but I am always near him when he wants to take his medications'. A description of the different roles played by each family member was given by the daughter of one of the patients, a 43-year-old unmarried woman living with her mother and working as a beautician: 'honestly all I have to do is let my youngest brother talk to her... she goes with him to see the doctor. I bring the prescription from the doctor's clinic for her; my sister brings the medications'. Another supporting statement of this interdependent role was stated by the only son caregiver in this study:

I take care of her but she has to take more care of her health. But thank God, I see her comfortable...my sister lives up, she comes to look after her sometimes, she helps her, she cooks, and she cleans. I go with her, we walk; I buy things for her like apple and fruits, and meat. It's better that I carry them than she carries them

The role of children was clearly stated by a participant, a daughter who works as shop assistant:

our role [as children] is very important even if our parents are not sick, children should take care of their parents, more so if they are sick...we keep an eye on them, their food, not to get tired, take them to the doctor, divide house chores not to make mama tired...

Even husbands had a share in the interdependent role as an 82-year-old husband clarified: 'now the responsibility is on me and her, of course; Sometimes I cannot go with her [doctor's visit], my daughter goes'.

Theme III

The third theme: *Multiple Supportive Roles* consisted of three subthemes each related to the three different supportive roles that the family caregivers played: the emotional role, the informational role and the instrumental role.

The *emotional role* consists of providing an emotional state of comfort and relaxation and avoiding worry and stress. It was verbalised by the 33-year-old son: 'I don't like to leave her; she might hurt herself or need something for example'; whereas the 45-year-old wife stated: 'if he gets angry, this might lead to an attack, ... I try to make him feel comfortable; I keep him on the bed. I elevate his legs. This way he relaxes and returns to normal'. The emotional role was perceived as well by hiding problems from the patient as the 50-year-old wife declared: '...as much as I can, I try to hide problems from him; he doesn't need to know about our worries and concerns'. Participants supported their sick patient at home by trying to keep their hope high as a daughter caregiver explained: 'I should not let her feel that she is sick It is very important to keep her hope high'. In addition, the emotional role was evident by the participants favouring their patient over self as shown by the words of a 36-year-old wife: 'I wish if I were in his place, he wouldn't be in this condition'; and another 40-year-old wife saying: 'I don't care for myself, all I want is my husband to stay for my children' sake. The home is not worth anything without the man'.

The *informational role* was illustrated by participants constantly reminding their patient of living a healthy lifestyle, the timing of the medications, and the doctors' appointment. One participant, the 40-year-old wife said: 'I always warn him that too much cold is not good for him; I tell him that it is not good for him to walk in the sun'; another participant, the 82-year-old husband described his role: 'my role is to make sure she is taking care of her health; she is not eating things that are not good for her. I don't want her to do things that are bad for her'. Children warn their parents by reminding them to take care of themselves as the son caregiver stated: 'I remind her of doctor's appointment...'; and the daughter of another patient declared 'we always tell her don't eat this, don't do this, try to walk better than work at home, remember what the doctor told you...'.

The *instrumental role* was related to buying and checking medications, and buying and preparing healthy food for the patient. The daughter of one participant who is a 40 year old beautician replied: 'I tell her to take care of herself, take the medication regularly, I give her the medication...I tell her not to carry heavy weight'. Another participant (son of patient) expressed his role by voicing out: 'I bring her the medication and I tell her today take half tablet of the blood pressure medication and ¾ tablet of the coagulation medications... I organize her medications... I go with her to the doctor'. Encouraging healthy lifestyle was another mission caregivers do like a daughter taking care of her sick mother said: 'I try to feed her healthy diet, I take care of her hands and feet. I always do pedicure for her...I put lotion on her feet and I cut her nails'.

Discussion

Lebanese family caregivers were unfamiliar with the term, concept and meaning of Self-Care; this finding is similar to that of their patients reported in another study in press. Caregivers reported that though their patients may be able to take care of themselves yet they get involved in giving care out of love, sympathy and family obligation, and that it was expected of them to do so. The care provided by the patients themselves as well as their family members was labelled 'interdependent self-care'. Interdependent self-care indicates a dyadic relationship between patient and family caregiver in performing a certain action (Buck *et al.* 2014).

Family members supported the self-care practices of their patients in several ways. While patients identified a specific family caregiver to be interviewed; all family members especially the ones living with their patients participated in providing support and care to their sick one. Family members who were identified as the primary caregivers were either one of the children or spouse, however, they were helped by other family members such as mothers and sisters of patients in providing care to their sick patient.

Participants' accounts showed that children provided actual support such as bringing or buying medication to their patients, cooking and cleaning the house on behalf of their patient mothers, and driving their parent to the clinic for the follow-up visit. This type of support is referred to as instrumental or tangible support by House (1987) who conceptualised social support into three types: instrumental, informational and emotional. Children also provided emotional support to their parents by calling to check on them, reminding them to take care, remaining by their side during hospitalisation and encouraging them to follow with doctor's instructions. Caregivers interviewed showed evidence that the children appeared overprotective of their parents, wanting them to stay sitting or resting without sharing in household chores. However, contrary to Condon and McCarthy's (2006) findings, these Lebanese parents did not seem bothered by their children's tendency to be overprotective. Consistent with Lebanese culture and family behaviours, the parents considered their children to be caring and were thankful to them (Dumit 2008).

The spouse roles in supporting cardiac self-care differed considerably between a husband and a wife in this study. The role of the wife encompassed planning and preparing meals for the patient husband and reminding him of his medications; this is consistent to what is reported by Heitman (2006) about the female role in overseeing healthy diets of family members with cardiovascular problems. Some wives reported accompanying their husband to the doctor's clinic, buying their medications and encouraging them to rest and exercise. On the other hand, husbands' roles were focused on giving advice to their wife patient and accompanying her to the clinic for follow-up. These findings suggest that the wives and female children play a major and significant role as caregivers in support of cardiac self-care as compared to the male family members. These findings are in concordance with those of Hwang *et al.* (2010) where the authors reported that caregivers are performed tasks such as assistance with medication administration and eating.

Participants reported that other family members provided actual and emotional support to their cardiac patient such as encouraging them to take care, getting them medication and checking on them. This finding is similar to that of Kristofferzon *et al.* (2007) who reported all family members including parents, siblings, grandchildren, nephews and nieces, and daughters/sons-in-law participated in the care of their cardiac patients.

Conclusion

Support by family members needs further investigation qualitatively and quantitatively to understand the process and the extent to which this family support influence independent cardiac self-care practices. A need exists to determine which family roles best facilitate and motivate self-care practices and which roles impede or delay it.

Social support, specifically family support, was a significant major factor affecting self-care practices of Lebanese cardiac patients in this study. Family members helped their cardiac patients perform self-care behaviours irrespective of the patient ability to do so. However, those patients did not refuse the help of their family members, and family members felt responsible for the health and care of their patients. It is worth mentioning that family members may tend to be overprotective, a behaviour/phenomenon that needs investigation in terms of its effects on self-care behaviours of cardiac patients..

Relevance to clinical practice

Nurses providing care to cardiac patients need to identify those family roles that facilitate and support cardiac self-care to integrate family members in the overall plan of care. Significant family members ought to be included when implementing interventions intended to develop and improve self-care practices of cardiac patients. Specific attention to the effect of the potentially overprotective role of the family members on patient independent self-care should be regarded by the health care providers congruent with the cultural norms.

Caring for Lebanese cardiac patients who value interdependent care must take into consideration the role of the family in supporting their self-care. Including the family in secondary prevention programmes of cardiac illness helps not only in enhancing the self-care of cardiac patients but also in addressing the potential overprotective role of family members. It is crucial for health care providers to assess those family roles that are complementary to the role of the cardiac patients and use assessment findings in planning self-care interventions.

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What does this paper contribute to the wider global clinical community?

- This study demonstrates that family caregiver role is grounded in the sense of obligation and duty towards the sick family member.
- Family caregivers' roles in a certain culture is assumed as a collective responsibility.
- Family members interdependently provide different types of supportive care.

Table 1Demographic characteristics of the participants ($N = 13$)

Family caregiver	Number
Gender and role	
Female	10
Wives	6
Daughters	4
Male	3
Husbands	2
Son	1
Age in years	
Range	33–82
Mean age	46.35
Educational level	
Read and write	3
Middle school	4
High school	6
Occupation	
Females	10
Housewives	6
Daughters	
Beautician	3
Shop assistant	1
Males	
Husbands	3
Retired	1
Clerical	1
Son mechanic	1

Table 2

Themes and categories of role of Lebanese family care-givers

Overarching cultural theme
Family caregivers of Lebanese cardiac patients were unfamiliar with the term, concept and meaning of Self-Care
Theme I: <i>Obligation and responsibility</i>
Moral and emotional obligation to take care of the other person even if he/she can take care of himself/herself
Shift of responsibility
Theme II: <i>Interdependent care as a cultural role</i>
Theme III: <i>Multiple supportive roles</i>
Emotional support
Informational support
Instrumental role

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