



Guest Editor: Prof. Doris SF Yu

Information needs of older people with heart failure: listening to their own voice

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According to a large-scale census in 2000, there were approximately 4,000,000 patients with heart failure (HF) aged between 35 and 74 years in China.^[1] Patient education shows its importance and essentiality in controlling the disease by improving the self-care abilities of patients.^[2] However, a shortened period of hospitalization compromises the effectiveness and efficacy of the education. It is therefore suggested that the information needs of patients with HF should be simultaneously addressed to make education more appropriate and tailored.^[3]

In essence, the “needs-based” approach has been supported as a way of educating cardiac patients.^[4] Learning need, defined by Knowles,^[5] is the gap between the specified competencies and the learner’s present development level. To assess the “gap”, the crucial element is the learner’s own perception of the discrepancy between where he or she is now and where he or she wants to be.^[6] Accordingly, educational strategies should be developed based on the assessment of the patients’ information needs so as to reduce the gap.^[6,7] Thus, the present study aimed to explore the underlying perceptions of information needs from the HF patients themselves.

The study was conducted in the cardiovascular department of a university-affiliated hospital in Xi’an, China. An exploratory qualitative study design was adopted by using face-to-face interviews to collect data from the patients. Patients with HF were selected according to the following inclusion criteria: (1) having been diagnosed with HF; (2) being able to understand Mandarin; and (3) willing to share and discuss their experiences. The patients who had signed the consent forms were invited to attend the interviews at a mutually agreed time. The interviews were guided by the

semi-structured questions. All the conversations were tape-recorded with the permission of participants. Content analysis was used to analyze the interview data.

A total of 26 patients with HF took part in the interviews. Detailed information about the demographic characteristics of the participants is shown in Table 1. Five categories together with the corresponding sub-categories are summarized and listed in Table 2.

Table 1. Demographic characteristics of the participants.

Gender	
Male	15 (57.7%)
Female	11 (42.3%)
Age	58.62 ± 11.09
Education	
Primary (1–6 yrs)	5 (19.2%)
Secondary (7–13 yrs)	10 (38.5%)
Tertiary (>13 yrs)	11 (42.3%)
NYHA classification	
II	10 (38.5%)
III	9 (34.6%)
IV	7 (26.9%)
Etiology	
CHD	9 (34.6%)
Cardiomyopathy	5 (19.2%)
CHD + Hypertension	3 (11.5%)
CHD + Cardiomyopathy	2 (7.7%)
Hypertension + Arrhythmia	2 (7.7%)
Rheumatic heart disease	2 (7.7%)
Hypertension	1 (3.8%)
Congenital heart disease	1 (3.8%)
Arrhythmia + Cardiomyopathy	1 (3.8%)

N = 26, data are presented as *n* (%) or mean ± SD. CHD: coronary heart disease; NYHA: New York Heart Association.

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Table 2. Categories and subcategories emerging from the interview data.

Categories	Subcategories
Living with inadequate information	Poor understanding of HF
	Inadequate knowledge of medication
	Uncertainty about coping strategies
Content of information needs	Risk factors
	Medication
	Disease management strategy
Motivators for information learning	Desire to improve their current health condition
	Obligations towards other family members
	Maintaining hope for the future
Barriers to information acquisition	Economic concerns
	Geographical inconvenience
	Material-related and patient-related factors
	Little communication with health professionals
Preference for information delivery	Direct communication with health professionals
	Written materials
	The internet
	TV programs
	Newspapers

HF: heart failure.

Poor understanding of HF. Most participants ($n = 24$) demonstrated unfamiliarity with and poor understanding of the term “heart failure”. Participants reported that they knew they had heart problems but they were not aware of HF. One participant even answered directly that he had no knowledge about the disease: “I have no knowledge of HF, is it one of the cardiac diseases? I think it is more serious...I cannot describe it [HF] clearly...I really don't know.”

Inadequate knowledge of medication. Among all the participants, there was only one female who could state clearly what medications she was taking, as well as the effects and side-effects of each medication. All of the other 25 participants, however, had similar responses: “...I do not care about the effects and side-effects! I also don't know the names of these medications. There are too many [medications], as you know. I just take them because they are prescribed by the doctors...”

Uncertainty about coping strategies. Participants indicated their uncertainty about the disease management strategies. They showed little knowledge about those strategies which could help to improve their health, as the following quote makes clear: “I have some queries. What foods are suitable for cardiac patients? What should cardiac patients pay special attention to? Should we exercise to a certain extent or totally rest without exercise?”

Content of information needs. When asked about the topics that they regarded as important to learn, all of the

participants showed a particularly strong desire to obtain information that could facilitate their self-management of the disease, as one participant stated: “...important topics?...I think that should be those that I need to pay attention to in my daily life, like diet, exercise, controlling my temper, and so on. How to protect myself and avoid risk factors is also important...I think it's more appropriate to express it like this: As long as I have ways to obtain the information, I hope I can get as much information as I can...”

Desire to improve their current health condition. The desire to improve their current health condition was one of the factors that motivated participants to learn the information related to HF. “...I have no problems with the lifestyle adjustment if only the disease can be controlled and I do not have to suffer from breathlessness. I am willing to learn and change as long as my condition can be improved.”

Obligations towards other family members. Participants thought that HF not only put care burdens on their families but also brought them apprehension. Feelings of guilt were especially expressed: “...I know I am living not only for myself, but also for others...I should give up my bad habit of smoking, I should be positive towards life...I should be responsible for my family members...I need to examine myself and change...I need to learn more information, the more the better, to effectively control it.”

Maintaining hope for the future. Although patients with HF experienced various discomforts, they still preserved hope for their future lives by stating that they would “make each day count” and “live with as little suffering as possible”. One participant described it like this: “...I think I have to get the disease cured at all costs because I am just 60, I can still live for another eight to ten years...”

Economic concerns. Participants described the high economic burden which the disease placed on them. One participant commented: “The economic issue is the only problem for me. You know, I have already spent a vast amount on treating the disease. Even worse is that the disease deprived me of my ability to work and I cannot earn money anymore. As a result, I cannot afford to buy the related materials to learn the information about the disease.”

Geographical inconvenience. Geographical inconvenience was also identified by two participants, of whom one lived in a rural area where the medical resources are limited and the other lived in a small town which is far away from Xi'an city. Just as one of them stated: “...there are really some difficulties...I live in a place which is not so developed, um, it is not a big city...we can only get the information from the newspaper or TV, the resources are too limited anyway.”

Material-related and patient-related factors. Material-related and patient-related factors were recognized as barriers that stopped patients from learning about HF, as in the following statements: “...if the word size is too small, I think I am not willing to read them as you know my vision is not that good, I have presbyopia.” “I cannot understand [the written materials] if the materials are too complicated because I have only a few years of education...the materials should be easy to understand, and they especially should avoid using terminologies of medical science...”

Little communication with health professionals. Health professionals, as described by the participants, provided brief explanations which failed to meet their needs and left them dissatisfied: “I asked the nurse what medications she gave me; she did not tell me and said she had no time to explain it to me...she told me that they [the medications] provided nutrition to my heart muscle...she said it was not my business to know about the medications and their effects...”

Preference for information delivery. The majority of the participants ($n = 22$) indicated that direct communication with health professionals was their favored way of obtaining information, as one female participant said: “I think direct communication with health professionals is better...but health professionals are always very busy, as you know. So...um, I think written materials provided by health professionals can also meet my needs. I can read them often and I will not forget the key points easily...”

The study indicated that Chinese patients with HF had inadequate knowledge related to HF, and this concurred with the previous studies in Western countries.^[8–10] The knowledge level of patients with HF can lead to problems of self-management, thereby resulting in a deterioration of their disease.^[11] The current low knowledge level of patients with HF should attract adequate attention from health professionals in China.

The content of information needs perceived by the patients with HF focused on prevention and strategies for controlling the disease in their daily lives. In China, patients treat health professionals as figures of authority.^[12] To show their respect for authority, the patients will trust the health professionals and obey all of the instructions given by them.^[13] Challenging authority is not an appropriate behavior in Chinese culture,^[12] and so it is not easy for patients to ask questions even though they have concerns. Health professionals should be fully aware of these true personal accounts when educating patients as part of their clinical duties.

Three motivators were identified in the present study. Influenced greatly by Confucianism, Chinese people clearly understand their roles in society as well as the responsibility

of those roles.^[14] When they cannot assume that responsibility for some particular reason, they will feel anxious or guilty about their failure to fulfill their responsibility, and these feelings could motivate them to learn more to manage their disease. Health professionals can foster the concepts of family obligation and of hope in order to optimize the effectiveness of HF education for Chinese patients.

Barriers identified by the participants were similar to those of previous studies.^[15–17] In reference to these barriers, health professionals should provide written materials in larger print, using terms that can be understood by laymen. It should be highlighted that quality rather than quantity is the key in the process of communication,^[18] and nurses play an important role here due to their 24-h access and excellent communication skills.

Written materials turned out to be the most acceptable way for patients to obtain information, and this corresponds with the reports of previous studies.^[9,17] These written materials can be designed to accord with the patients’ needs by covering the possible topics discussed previously. Patients can read the materials as many times as they need to reinforce their learnt knowledge.^[17,19] Accordingly, the key points are not easily forgotten by the patients, albeit that cognitive impairment is common among the HF population.^[20]

In conclusion, patients with HF in China had little knowledge of the disease and the coping strategies which are necessary to manage their disease. It is crucial for health professionals to understand the information which the patients need, how the patients prefer to receive the information, and what are the motivators and barriers. Based on this understanding, health professionals can as far as possible address the concerns of this specific population, thereby targeting their patients’ needs when designing and delivering the culturally relevant support and education.

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