

Behavioral involvement and preference for information among male and females with cardiac disease^{*#}

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ABSTRACT

The aim of this pilot study was to explore and compare preferences for involvement and preferences for information among men and women who had suffered from cardiac disease. A convenience sample of 79 respondents (47 men and 32 women) was recruited from The National Association of Heart and Lung Patients in Sweden at ten local meeting places in different areas. Krantz Health Opinion Survey, KHOS, a 16-item self-rating questionnaire, was used to measure patients' desire for involvement in healthcare. The results indicate that patients' information preferences and behavioural preferences are not very high though the total score in KHOS was 5.47. A difference between the genders was also found, seen as higher scores in females than males; 5.93 vs 4.44, $p = 0.032$, indicating that women prefer a more active role in decision making than men do. The main practical conclusion drawn from this empirical study is that patients are still not as active in seeking information or in behavioural involvement as is desirable.

Keywords: Heart Diseases; Krantz Health Opinion Survey; Gender; Information; Involvement

1. BACKGROUND

A high level of quality regarding patients' information and education is one of the most important parts in health care [1,2]. Preference for information and patients' willingness for involvement in their own care in particular play an important role in helping the patient to become actively participant in his/her own care by ensuring that he/she has the knowledge in order to be responsible for the care [3]. To provide tailored information and educa-

tion to the patient leads to increased patient knowledge [4], satisfaction [1] as well as improve patient medication adherence [5]. Patients' preferences for involvement are influenced by different factors [6,7] and it has been reported that women prefer a more active role in decision making than men [7-10]. Some studies have also showed that younger patients and patients with higher levels of education prefer a more active role [9,11].

The patients' role within the health care services has changed from a passive recipient of information and decisions to an active participant in the clinical decision making process, which is in line with the fundamental principal of evidence based medicine [12]. Patients are nowadays to a greater extent active in seeking information and support through the internet [13] and through membership of a patient association [14]. One important objective of a patient association is to provide information and support about appropriate diagnosis and treatment [15,16]. Carlsson *et al.* [14] found out that the cancer patients' motives to become and remain a member of an association were the predominant need for information. This could indicate that the patients' need for information is not sufficiently fulfilled by the professionals in health care and the need for access to information exists over a long period of time [16]. Providing patients with information and advice relating to health, lifestyle, illness and its treatment could be a complicated issue for healthcare professionals when patients are seeking additional health information through the internet [13] and through a patient association. However, people who usually are active in seeking information or in behavioural involvement tend to receive less knowledge than more passive patients *i.e.* more active persons already have health-related knowledge and knowledge about the certain care and therefore do not think they need any new knowledge [3]. A major challenge for the healthcare professionals, in facilitating patient participation, is thus to provide tailored information and education in line with the patient's needs and

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prerequisites [3,9]. Critical attributes for patient participation in health care includes an established relationship, respect for the individual, recognition of the individual's knowledge and circumstances as well as shared information [17-22]. Although, the value of patients' preference for information and patients' willingness for involvement in their own care has been demonstrated in many areas of health care, there appears to be a lack of research about the preferences for information and involvement in health care among patient association members.

Aim

The aim of this study was thus to explore and compare preference for involvement and preference for information among men and women who suffered from cardiac disease.

2. METHODS

2.1. Design and Setting

The study had an explorative and comparative design and was carried out during the spring of 2007 at The National Association of Heart and Lung Patients in Sweden. The latter is a non-profit organization working for the goal of quality of life for people with heart and lung diseases.

2.2. Sample and Data Collection

A convenience sample of persons was recruited from The National Association of Heart and Lung Patients at ten local meeting places in different areas in both urban and rural parts of Sweden. The aim was to recruit ten respondents at each local meeting place. A majority (80%) of the members of the National Association of Heart and Lung Patients are >65 years of age [23]. The inclusion criteria was that the respondents had own experiences of cardiac disease. At each meeting, a member of the research team informed the respondents about the study and asked the respondents to complete the questionnaire. No financial support was given to the respondents. The study was preceded by careful assessment of predictable risks and burdens and the importance of the objective was considered to outweigh the inherent risks or burdens for the respondents. The study was conducted according to the ethical principles of human research by the Swedish Research Council and according to the rules of the Helsinki Declaration on informed consent and confidentiality. The respondents were informed about the purpose and the structure of the study, after which they gave their informed consent. Participation was voluntary and the respondents were informed that they could withdraw from the study at any time.

2.3. Questionnaire

Krantz Health Opinion Survey (KHOS) is a 16-item self-

rating questionnaire, including two subscales, which measure patients' desire for involvement in healthcare. The Information subscale (KHOS-I) consists of seven items and measures the patients desire to ask questions and be informed about medical decisions. The Behaviour involvement subscale (KHOS-B) includes nine items relating to behaviour control preferences for involvement and self-initiated action in healthcare situations. The respondents rate their answers in a forced-choice format as agree or not agree. The total maximum score is 16:7 in KHOS-I and 9 in KHOS-B. Higher scores indicate greater need for information seeking as well as preferences for control in healthcare situations [24].

The reliability and validity of KHOS have been evaluated in a number of studies [3,24-26] showing an internal consistency reliability for the total scale between 0.68 to 0.77 [3,24], for the KHOS-B 0.55 to 0.78 and 0.56 to 0.76 for the KHOS-I [3,24,25,27,28]. The test-retest reliability was also satisfactory [3,24,29]. The instrument has also been evaluated in a Swedish context and showed a good internal consistency reliability for the overall scale 0.71 and the subscales 0.72 and 0.73 as well as moderate test-retest reliability [30].

2.4. Statistical Analysis

Continuous variables are presented as means and standard deviation. The KHOS-I and KHOS-B were analyzed by calculating the means of the corresponding variables. Mann-Whitney-U was used in order to test for differences between the genders. A p-value < 0.05 was considered to indicate a statistically significant difference. Statistical analyses were performed using the SPSS software 17.0 (SPSS Inc. Chicago, IL, USA).

3. RESULTS

The final sample consisted of 79 respondents, 47 men and 32 women, which gave a response rate of 79%. Total score in KHOS was for the present sample 5.46 (SD 2.8 range 0 - 16). There was a difference between the genders seen as higher scores in females than males; 6.22 vs 4.94, $p = 0.032$ (**Table 1**).

In KHOS-I the mean for the present sample ($n = 79$) was 3.03 (SD = 1.7 range 0 - 7). There were no differences between genders (**Table 1**). The statement that most of the respondents agreed with, representing active information seekers was: "I usually ask the doctor or nurse lots of questions about the procedures during a medical examination" (63%). The statement that most of the respondents agreed with, representing active information avoiders: "I usually wait for the doctor or the nurse to tell me the results of a medical examination rather than asking them immediately" (75%).

In KHOS-B the mean for the present sample ($n = 75$)

Table 1. Gender differences in Krantz Health Opinion Survey (KHOS) and the two subscales KHOS-I* and KHOS-B**.

	Min-Max	Females n	Females Mean (SD)	Males n	Males Mean (SD)	p-Value
KHOS	0 - 16	32	6.22 (3.1)	47	4.94 (2.5)	0.032
KHOS-I	0 - 7	32	3.22 (1.7)	47	2.98 (1.7)	0.380
KHOS-B	0 - 9	32	3.00 (2.4)	47	2.04 (1.5)	0.089

*KHOS-I = Krantz Health Opinion Survey, preference for Information; **KHOS-B = Krantz Health Opinion Survey Behavioral Involvement scale.

was 2.43 (SD = 2.0, range 0 - 7). There were no differences between genders (**Table 1**). The statement that most of the respondents agreed with, representing active involvement and self-initiated action in healthcare situations was: “*Except for serious illness, it is generally better to take care of your own health than to seek personal help*” (70%). The statement that most of the respondents agreed with, representing a passive involvement and self-initiated action in healthcare situations was: “*It’s almost always better to seek personal help than to try to treat yourself*” (94%).

4. DISCUSSION

The results of this study showed that there were differences in the total scale between female and male. This indicates that women prefer a more active role in decision making than men, which concur with the findings in previous studies [7,9,10]. However, in the present study the KHOS score for the total sample, 5.47, was lower than that in earlier studies [24,31]. Even preference for information, KHOS-I, was lower, 3.09, compared with earlier studies among patients, receiving hemodialysis treatment [32], ambulatory surgery patients [3] as well as among myocardial infarction patients [28]. One reason for these results could be that the persons included in this study have had the opportunity to seek information in different ways over a longer period of time since the cardiac event. Another reason could be that the membership of the National Association of Heart and Lung Patients [23] provides the persons with the opportunity to receive continuing information in this field, and therefore the need for information seeking might be lower compared to other groups of patients. However, Sjöström-Strand *et al.* [33] have reported that 5 years after a myocardial infarction women are still worried about all the drugs they have to take and suggest that a physician should have provided better information about the need for taking all these drugs.

More than half of the respondents in the present study agreed with the statement that they asked the healthcare staff questions about the procedures during a medical examination. However, three quarters of the respondents preferred to wait for the healthcare staff to inform them of the results of medical examinations. In a previous

study by Kentel *et al.* [34] it is reported that patients expect the physician to understand their situation and carry out appropriate actions, leading to a diagnosis and treatment as well as complete information regarding the patient situation. Patients want to influence and take responsibility for their own care and want this wish to be respected [1]. To participate and be actively involved influences their perception of satisfaction (ibid) It is thus of great importance that the healthcare staff are well-educated and have the necessary skills to inform patients as well as their partners [35], and that they use their intuition to understand the patient’s unexpressed questions and needs [1]. Furthermore, the healthcare staff should help the patients to get involved in their own treatment and provide them with information about their health situation so they can play an active role in their own care [3]. One way is to create an educational climate in health care organizations, where the staff view the patients as learners in order to help the patient achieve a state of preparedness, which is described by Friberg *et al.* as a cognitive-emotive-existential state and emphasized as an important goal in patient teaching [36].

In our study the mean for the present sample concerning preference for behavioral involvement was 2.43, which is similar to that in earlier studies [3,28,32]. There were no differences between sexes in the two subscales. No differences between sexes has been found by van Wijk *et al.* 2010 [37]. Yet, differences concerning age has been reported *i.e.* younger male patients who underwent elective coronary bypass surgery rated a higher level of desire for information than older male patients [38] and younger patients have been reported to be more anxious about being behaviorally involved in their treatment and self-care than older patients [3]. However, no examination of age differences was carried out in the present study as the members of the National Association of Heart and Lung Patients are 65 years of age or older.

Most respondents agreed with the statement that it is better to seek healthcare than try to treat themselves. On the other hand Lovlien *et al.*, [39] found that 33 percent of women and 25 percent of men self-medicated against discomfort before seeking treatment when they had their first acute myocardial infarction and thereby generating a delay between the onset of symptoms and hospital admission. The divergences may be because of the mem-

bers of the National Associations of Heart and Lung Patients had own experience or been close to others' experience of one or more cardiovascular events and are more likely to seek medical care quickly if serious illness occurs.

There are some limitations to the present study. Firstly, the KHOS questionnaire has a binary scale which leads to some limitation for the statistical analysis. However, KHOS is easy to use and has been extensively tested. Secondly, background characteristics of the respondents such as age, education levels etc. are unknown. Finally, the sample size was small despite recruiting from different areas of Sweden. Nonetheless, a larger national survey would provide a more solid basis for the development of patient education. It would also be valuable to further investigate whether there are associations between patients' desire for involvement in healthcare and associated phenomena, such as quality of life, anxiety and patient satisfaction with care. There is also a strong necessity for additional research of the use of the questionnaire in other patient populations which should include younger patients, as well as patients from other cultures, where involvement in their own care may not be as common or as desirable.

5. CONCLUSION

The main practical conclusion drawn from this empirical study is that even today, patients are still not as active in seeking information or in behavioural involvement as is desirable. Registered nurses and other healthcare staff have thus a major challenge in order to get the patients involved in their own treatment by supporting and providing them with information about their health situation so they can play a more active role in their own care. This also includes checking that the patients have received information that is comprehensible and have been given the opportunity to ask questions.

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