Sexual Counseling in Patients With Heart Failure A Silent Phenomenon: Results From a Convergent Parallel Mixed Method Study

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1. Introduction

Living with heart failure has a significant impact on everyday activities and requires patients and their partners to make considerable changes in their lives¹⁻⁵. Sexuality, might not always be seen as first priority when suffering of heart failure, still sexuality is a part of everyday life of a lot of chronic patients and satisfaction with one's sexuality is an important component of quality of life⁶.

Many heart failure patients experience problems with sexual activity as a result of their condition, medications, or anxiety⁷. They may worry about resuming sexual activity and may be in need of education and counselling regarding this issue^{3,6,8}. Patients with HF, and their partners, wish to receive information from health care providers about resuming sexual activity after being diagnosed^{8,9}. Recently published international heart failure guidelines and statements recommend that healthcare providers should discuss sexual health with their patients¹⁰⁻¹².

Nurses play an important role in assisting patients to adapt their lifestyles and to learn how to live with their disease^{4,14,15}, which should include sexual counselling to heart failure patients^{3,16,17}.

Several European studies (e.g. the Netherlands, Belgium, Denmark, and Ireland) and studies from the United States described the perceptions of cardiac nurses regarding their roles in discussing sexual concerns with their patients^{13,16,18-21}. Although most nurses in these studies reported feeling responsible for discussing sexual concerns, they rarely do so in daily practice^{13,16,18-21}. Nurses reported overall discomfort discussing the subject including a lack of knowledge and skills, specifically not knowing on how to initiate a discussion about sexual concerns^{13,22}.

In addition, organisational factors may be a contributing factor, hindering nurses to start a discussion about sexual concerns with patients, such as a lack of time and/or a lack of privacy in hospital settings^{13,20}.

Another factor influencing discussions of sexual concerns with heart failure patients could be the cultural background: in countries, where attitudes towards peoples' sexuality are more liberal, nurses might be more

likely to discuss sexual concerns than in more conservative countries ¹⁶. Furthermore, the education of nurses plays an important role in the discussion of sexual concerns, with higher educated nurses feeling more comfortable in discussing sexual concerns ^{13,21}. Nursing education varies significantly across European countries ^{23,24}. In a recent study, Aiken and colleagues (2013) reported that in 11 out of 12 European countries a minimum of 20% of nurses working in clinical settings have bachelor's degrees; with the exception of Germany, there was no nurse with bachelor degree. Health care models differ as well. In a Dutch study by Hoekstra et al. (2012) the majority of nurses (74%) agreed that the preferred time of discussing sexual concerns is during a follow-up visit at a nurse-led heart failure clinic. In contrast to nurse led clinics in many countries follow-up visits following hospital discharge in Germany are generally provided by physicians ²⁵. As a result of this German nurses may have different perceptions on sexual counselling of heart failure patients. Accordingly, the purpose of this study was to examine whether German cardiac nurses discuss sexual concerns with their heart failure patients, and if they do not, to explore their reasons. Therefore, we aimed to: (i) investigate practise, responsibility and confidence on sexual counselling of nurses working with heart failure patients in German hospitals or **inpatient rehabilitation centres and how they estimated comfort of their patients related to sexual counselling**; and (ii) explore their perceived roles, responsibilities, and barriers regarding this topic.

2. Methods

2.1. Data collection and study population

A cross-sectional study design with a convergent parallel mixed method ²⁶ approach was used, combining qualitative and quantitative data collected with a self-report questionnaire. Quantitative data was collected using the sexual counseling instrument of the 'Undertaking Nursing Interventions Throughout Europe' (UNITE) research group of the European Society of Cardiology ¹⁸. Two open ended questions were included to explore how nurses understand their roles in discussing sexual concerns with patients **and what barriers they have**

experienced. Additionally, an eight-item questionnaire developed by the researcher was used to collect data on socio-demographic information and professional background.

Participants were recruited through the German Heart Failure Nurse Working Group and by contacting hospitals and all inpatient rehabilitation centres specialized in heart failure. After obtaining institutional review board approval from each hospital and inpatient rehabilitation centre, potential study participants were invited to this study through an introductory cover letter explaining the purposes for this study, **requirement for study participation**, and providing instructions for completing the questionnaire. Nurses were eligible for participation if they worked with heart failure patients, were employed as a nurse in a hospital or **inpatient** rehabilitation centre in Germany, and were able to understand and read German. **After four weeks, the investigator contacted the contact persons via e-mail or telephone to remind them to collect the data and to check for potential problems in data collection.** The study complied with the principles outlined in the Declaration of Helsinki and was approved by the ethics committee of the German Society of Nursing Science.

The UNITE sexual counseling instrument

To measure the perceptions of German nurses in practice, their responsibilities, confidence, and **how they estimated comfort of their patients** regarding sexual counselling, the UNITE sexual counseling instrument¹⁸ **was used. This reliable instrument²⁰ was in part based on the ‘nurses’ survey of sexual counselling of MI patients²⁰ and** has been used in previous studies^{13,16,18,20}. **It consists of four subscales:** practice, responsibility, confidence, and perceived comfort of the client¹⁸. The subscale ‘practice’ includes 8 items: four of them are scored from 0 to 3 (**responses range from “never” to “always”**) and four are scored from 0 to 5 **with a subscale range of 0 to 32.** Higher scores indicate better performance in sexual counselling. On the subscale ‘responsibility’ (5 items) all items are scored from 0 to 4 (**responses range from “strongly agree” to “strongly disagree” or “never” to “always”**)

with a subscale range of 0 to 20. Higher scores reflect a higher sense of responsibility to initiate sexual counselling with patients. The subscale 'confidence' consist of five items, being scored from 0 to 4 (**responses range from “strongly agree” to “strongly disagree”**) **with a subscale range of 0 to 20.** Higher scores reflect higher confidence of nurses to discuss sexual concerns. The last subscale (4 items) indicates how nurses estimate the comfort of their clients when discussing sexual concerns. The items are scored from 0 to 4 (**responses range from “never” to “always”**) and higher scores (subscale range 0 to 16) indicate lower comfort of their patient ¹⁸.

Using Cronbach's alpha reliability of the subscales have been reported: practice (0.89), responsibility (0.75), confidence (0.79), and the estimated comfort of the clients (0.79)²⁰.

German version of the UNITE sexual counseling instrument

The UNITE sexual counseling instrument ¹⁸ was translated into German using standard translation procedures ²⁷. First, two nurses with excellent English language competence translated the instrument into the target language (German). These two versions of the scale were compared and merged into a single forward translation. It was then translated back into English by a nurse who is also a native speaker. The back-translated version of the instrument was compared with the original one, without finding any substantial discrepancies. We tested the German version of the instrument on a small group of nurses (n=12) in order to check comprehensibility and interpretation of the translation by discussing every item with them. None of the nurses described difficulties.

Internal consistency reliability of the current study subscales using Cronbach`s Alpha were 0.85 for practise, 0.79 for responsibility, 0.73 for confidence and 0.82 for perceived comfort of clients. Content validity for subscales were computed on responses from a panel of four experts using the Content Validity Index (CVI): practice (0.88), responsibility (0.81), confidence (0.81), and **perceived comfort of client (0.81)** (see ²⁸, p. 423).

2.2. Quantitative data analysis

Standard descriptive statistics including means, medians, and ranges were calculated for all of the quantitative variables using SPSS version 20.0. Nominal and ordinal data are presented as absolute numbers and percentages. The results of the four subscales (ordinal data) are presented as medians and interquartile ranges. **We only computed the total scores of the subscales, if 80 % of items of that subscale were completed by the respondents.**

2.3. Qualitative data analysis

A content analysis of **the open ended questions** “Which role do nurses have in sexual counselling of heart failure patients?” and “In your opinion, why do you think sexual counselling of heart failure patients rarely occurs?” was performed based on the summarizing methods ²⁹ **to identify perceived roles, responsibilities, and barriers.** The total data were analysed by the first author and then discussed with one of the other authors and within a peer-group. A concept map was created by extracting phrases from the original answers, abstracting them into codes by summarizing related phrases. The codes were grouped together to form categories. After categorization of the data, the researchers returned to the individual level to ensure that the categories were differentiated at an equal level of abstraction. The analysis was an inductive process, and the goal was to create a description and list of categories related to the phenomenon under investigation.

2.4. Mixed method analysis

To explore perceived roles, responsibilities, and barriers nurses have regarding to sexual counselling in patients with heart failure, we mixed the data sets following the convergent parallel design ²⁶. The phenomenon “responsibility” – differing from low to high - was represented in both data sets (**quantitative and qualitative**). Regarding to discuss sexual concerns with HF patients ‘feeling responsible’ seems to be a precondition. **To bring together a more comprehensive account regarding to the differences in feeling responsible or not and to have a better understanding of the context of that, firstly, we**

split up the data focusing on nurses who unambiguously show a tendency in feeling more or less responsible in discussing sexual concerns. Regarding to this, we only included participants feeling lower responsible ($x \leq 8$) at the sub score *responsibility* of the German version of the UNITE sexual counseling instrument and higher responsible ($x \geq 12$). Secondly, we analyzed the open ended answers of this two datasets (lower and higher scorers regarding *responsibility*) a second time separately following content analysis²⁹, and thirdly, compared these results, to identify if there were differences or not in-between these two groups.

3. Results

3.1. Response rate

In total, 211 of 467 questionnaires were returned (response rate: 45%). Of the 211 nurses, 147 replied to the open-ended questions. These data were used in the content analysis. The data of 54 respondents who reported lower ($x \leq 8$), and 46 who reported a higher responsibility ($x \geq 12$) in the subscale responsibility were included in the mixed method analysis.

3.2. Sample characteristics

The mean age of the nurses was 39 (SD=11) years, and 89% were female. Most nurses worked in a cardiology (62%), or general medicine (12%), and 5% worked in in-patient rehabilitation centres. The majority of the respondents had been working in nursing for more than 6 years (75%), and 31% had worked with heart failure patients for more than 15 years. In total, 42 (20 %) had additional training in heart failure. (table 1)

3.3. Practice, responsibility, confidence and comfort of their patients

Nurses scored a median of 3 in the subscale 'practice', indicating that most of the nurses never or rarely addressed sexual issues. (table 2) In total 50% of the nurses reported rarely answering questions ($n=111$; 53 %) or listening to patients' concerns about sexual

problems (n=104; 49%). Most nurses disagreed that it was their responsibility to discuss sexual concerns with their patients (median=9). More than 50 % (n=111) of the nurses reported that in case the patients initiated a discussion they would discuss sexual concerns (see figure 1). With regard to confidence, 75% of the nurses reported a total score of 10 or less, meaning that they rather feel uncomfortable in discussing sexual concerns. Only 8% reported a higher score than 12 indicating that they felt confident in discussing sexual concerns with patients. Nurses estimated a low comfort of their clients when discussing issues about sexuality (median 9). (figure 1)

3.4. Barriers, and factors related to discuss sexual concerns

From the qualitative analysis an overall concept influencing all other factors in discussing sexual concerns was derived, namely that sexuality is described as a topic that no one talks about. According to the nurses' statements, neither they, nor the patients, initiate a discussion related to sexual concerns. Sexuality seems to be a silent phenomenon. Although this phenomenon is silent, the role of nurses is described in different ways, ranging from not being responsible to being responsible. **Comparing nurses feeling lower ($x \leq 8$) or higher ($x \geq 12$) responsible with respect to factors influencing the silence of phenomenon and the perceived role of nurses in discussing sexual concerns with patients, we identified differences and commonalities being summarized in table 3.**

Silence of the phenomenon

Respondents explained, that discussing sexual concerns is often described as an absolutely private topic, one that leads to embarrassment, shame, and uncertainty. Sexuality is perceived as a taboo, and because of this, nurses and patients are inhibited to talk about it. Nurses reported to be afraid about putting themselves or their patients in an unpleasant situation when initiating a discussion about sexuality. "... *I am afraid to bring patients (and myself) in an unpleasant situation*" [65]. Nurses felt that they were not adequate trained in discussing sexual concerns, resulting in refraining from starting conversations about this topic. If nurses

did not feel responsible for discussing sexual concerns with their patients ($x \leq 8$), and did not recognize this as being a part of nursing, they did not initiate such conversations with their patients. Additionally the assumed relevance of this topic for heart failure patients influences the phenomenon of silence. If nurses thought that their patients are too old, too ill or are not interested in sexual activity anymore, nurses stated that they will not talk about it. “... *Patients never ask anything about sexuality, because they are very old [and do not have sex anymore]*” [141]. Nurses also described that patients with heart failure in an acute situation in hospital have other problems, like physical stabilisation or survival. The mixed method analysis added that especially nurses who felt a low responsibility in discussing sexual concerns described that heart failure patients never asked or commented on anything regarding this topic. Additional barriers for discussing sexual issues were related to the organisational structure. Patient education related to sexual concerns could not always be realized in hospital, because of a lack of time, a lack of space to discuss such intimate topics privately, and the hospital length of stay being too short. “... *We do not discuss sexual concerns with patients, because there is a lack of time in daily practice, patients will stay in hospital only a few days, and another problem is that we mainly have at least double rooms*” [124]. Nurses reported that sexual concerns should be discussed in an in-patient rehabilitation centre or in primary care, but not during hospitalisation.

Roles of nurses in discussing sexual concerns with patients

The roles of nurses in discussing sexual concerns with heart failure patients were described differently. On the one hand, nurses who scored low ($x \leq 8$) on the subscale responsibility described that it was not their role to discuss sexual concerns with their patients. They did, however, feel that if patients took the first step and asked questions, they were responsible for responding. “...*if patients have questions related to sexual activity, I usually answer them, but they have to initiate this discussion*” [88]. Consequently, they would provide information or refer the patients to physicians or other health care professionals. They believed that

discussing sexual concerns rather belongs to trained experts. “... *I think this topic should be discussed with well-trained experts and because of this it is not part of my job; I have a lack of knowledge*” [60]. A lack of *knowledge and communication skills*, decreased the nurses’ perceived responsibility to discuss sexual concerns. On the other hand, the nurses feeling responsible ($x \geq 12$), believed that they have to do more than just responding to patients’ questions. They used holistic approaches in nursing, where nurses are responsible for educating and preparing patients for everyday life with the disease. “...*I have a very important role in discussing sexual concerns with patients, because I am a nurse and we have the responsibility to educate and counsel patients and sexuality is part of it – it is also an activity of daily living*” [70]. Some of these nurses also described the high relevance of this topic particularly for younger patients. Nurses feeling responsible ($x \geq 12$) also reported that there extra skills were needed to feel more comfortable in discussing sexual concerns and to educate patients in a better way. “... *It is a very important topic and nurses have a high responsibility, because it is part of patient education...But nurses often have a lack of training in this topic*” [161]. Finally, nurses described that discussing sexual concerns with patients requires trust between health care provider and patient. Factors influencing this *relationship* were gender and age. Nurses reported that the fact that most of their patients are older men, and most of the nurses are younger women, might influence the discussion. Furthermore, the short length of stay might make it more difficult to build a trusting therapeutic relationship, critical to the discussion of sexual concerns. Nurses believed that they were in a good position to have a good therapeutic relationship with patients, since they are generally the first contact for patients’ questions, on a 24 hours basis. They also reported that male doctors in particular might have another relationship with patients making them more suitable to discuss questions related to sexual concerns. “...*I only have a small role in discussing sexual concerns with patients, because patients, who have a question about their sexuality, are male most of time*

and it is embarrassing for them to ask me (they would rather ask the physician at the visit)”
[88].

4. Discussion and Conclusion

4.1. Discussion

Contradictory to several studies, the results of this study found that more nurses do not feel responsible for discussing sexual concerns with their patients and only a few of the nurses expressed confidence in this area. Rather uniquely, in our study, 75 % of nurses reported that they felt not prepared to discuss sexual concerns with their patients. Not only do they feel insecure and uncertain how to initiate conversations related to sexual concerns, they report that they would need further education in this area, to increase their knowledge, and to develop appropriate communication skills.

The main issue in discussing sexual concerns seems to be a phenomenon that is ‘silent’: No one talks about sexual concerns related to cardiac disease and talking about sexuality is perceived as a taboo. Factors influencing this situation include structural barriers, a lack of knowledge and communication skills, the self-concept of nursing, relevance of the topic and relationship to the patients. At first sight these German results are comparable to other studies in health care providers working in cardiac rehabilitation, where about 95 % of nurses found sexuality too private to discuss with patients ¹⁹. We also confirmed that even when cardiac nurses believed that discussing sexual concerns with their patients is their responsibility the majority of them never, or rarely do ^{13,16,18,21,30}. Interestingly, we also found in our mixed method analysis, that nurses, who felt less responsible for discussing sexual concerns with their patients, actually did not see sexual counselling as a dimension of their role as nurse. Higgins et al. (2006) described that nurses first of all have to legitimize sexuality as an important aspect of care. Nurses who feel less responsible first have to develop a new self-concept of nursing and only then can increase their knowledge and skills regarding sexual counselling. Then it would still be a demanding task to create a care context that conveys to

the patient that sexuality is a suitable subject to talk about ³¹. Nurses in this study reported that barriers to create a context for discussing sexual concerns were related to the organisational structure. This included a lack of time patients only staying for a short time in the hospital, and no privacy to discuss sexual concerns. Some nurses believed that sexual concerns should be discussed in an in-patient rehabilitation centre or in primary care. Hoekstra and colleagues (2012) identified a lack of organisational policy as the most prominent barrier in discussing sexual concerns. In their study, 74 % of nurses agreed that sexual health should be assessed during a follow-up visit at a heart failure clinic. But in Germany follow-up visits focussing on patient education and counselling are not an integral part of health care. Some nurses in our study reported, that if patients are in hospital they may have other more acute problems, leaving discussions about sexuality a lower priority for nursing care. However, if the hospital is the only place, where patients could discuss such topics with health care providers, we have to find a solution to this dilemma. As shown in our results, ‘breaking the silence’ seems to be the main challenge in this dilemma. Based on our findings in the mixed method analysis, nurses who feel a low responsibility for discussing sexual concerns first need to recognize sexuality as an aspect of professional nursing. For those nurses who do feel responsible, one solution to break this silence might be special training regarding sexual counselling. Development of knowledge, skills, and competencies can positively affect health care provider’s attitudes to discuss sexual concerns ^{32–34}. Nurses with additional training on sexual counselling are more likely to discuss sexual concerns and feel more comfortable in this regard ¹⁸. Also **from other studies it is known**, that cardiac nurses with higher levels of education showed a tendency in practicing sexual counselling more often ^{13,21}, which might suggest that these nurses had greater access to train their counselling skills and competencies, and thus, might be more willing to engage into discussions about sexual concerns ²¹. Because the majority of nurses in our study believed that their patients would be upset, embarrassed or anxious if they were asked about

sexual concerns, the provision of written materials dealing with sexual problems might be a particularly useful strategy to enable nurses to raise sexual issues in a non-threatening way and give patients the permission to raise questions ^{35,36}. Such approaches however, should be considered not being a substitute for personal discussions. By creating a climate of permission, discussing sexual concerns might open channels of communication for both nurses and patients ³⁶.

4.2. Limitations

This study has several limitations. Firstly, the aim of this study was to identify perceptions of nurses in hospitals, and in in-rehabilitation centres. **However, our sample contained only 5.2 % of nurses working in an in-patient rehabilitation centre. It might be that the contacted persons in this area did not see any relevance of this topic to their clinic. For example, some of them answered that this is a topic being not discussed with patients during rehabilitation.** This is contrary to previous research which has shown that cardiac rehabilitation staff may be more likely to discuss sexual concerns than nurses in other areas ^{21,30}. Also we had a heterogeneous self-selected sample with a size of 211, which is comparable to other studies regarding this topic, we only acquired information about nurses who did response, but there is no information on nurses, who did not. **At first glance the response rate of 45 % seems to be low, but in comparable studies response rates of 33% to 41% were achieved^{13,18,21}.** Second, since the qualitative items were added to the quantitative instrument, as such these items do not represent a complete context-based qualitative data-set. However, this convergent mixed method design provides researchers with emergent themes and interesting quotes that can be used to validate and embellish the quantitative findings ²⁶. **Accordingly, the results may not be generalizable for German cardiac nurses beyond this sample and should be interpreted with caution.**

4.3. Conclusion

Cardiac nurses in Germany rarely practice sexual counselling. It is a phenomenon which is silent. They are inhibited to talk about such a taboo topic, feel not responsible in discussing sexual concerns or feel not well prepared. Regarding to the results of this study, nurses are in need of specialized knowledge and communication skills to feel comfortable to discuss sexual concerns with heart failure patients. Education and skill-based training might hold potential to 'break the silence'. To develop a purposeful training program for nurses as well as targeted tools for the patients, future research should clarify how, with whom, and when patients would like to discuss this topic especially in areas where follow-up visits are not an integral part of usual care.

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Figure legend

Figure 1: Nurses' perceptions of their responsibility to discuss sexual concerns

Table legend

Table 1: Sample characteristics

Table 2: Results of the subscales of the questionnaire

Table 3: Role of nurse and silence of phenomenon: An overview of the results of the mixed method analysis

Figure 1: Nurses' perceptions of their responsibility to discuss sexual concerns

Table 1: Sample characteristics (n = 211)

Demographics

Women 188 (89.1 %)

Age (n = 199*) 38.6 (SD 11.2)

Work place (n = 210)*

Cardiology 130 (61.6 %)

General medicine ward 26 (12.4 %)

Cardiothoracic surgery 11 (5.2 %)

Critical Care Unit 17 (8.1 %)

Rehabilitation 11 (5.2 %)

Other 15 (7.1 %)

Work experience in nursing

0 – 11 months 6 (2.8 %)

1 - 5 years 36 (21.8 %)

6 – 15 years 54 (25.5 %)

More than 15 years 105 (49.8 %)

Work experience in cardiology

0 – 11 months 13 (6.2 %)

1 – 5 years 62 (29.4 %)

6 – 15 years 68 (32.3 %)

More than 15 years 65 (30.8 %)

Special training in heart failure 42 (19.9 %)

Heart Failure Nurse: 23/42

others: 19/42

*number of responses, in cases data are missing

Table 2: Results of the subscales of the questionnaire

Subscale	Score	Median (Q1 – Q3)
Practice ¹	0 - 32	3 (1-6)
Responsibility ¹	0 - 20	9 (7-12)
Confidence ¹	0 - 20	8 (6-10)
Perceived comfort of clients²	0 - 16	9 (8-10)

¹higher scores indicate higher practice, responsibility or confidence; ²higher scores indicate lower comfort of the nurses' clients

Table 3: Role of nurse and silence of phenomenon: An overview of the results of the mixed method analysis

Role of nurse in discussing sexual concerns with patients		Silence of phenomenon Neither patients nor nurses talk about sexual concerns.		
Nurses feeling a lower responsibility to discuss sexual concerns ($x \leq 8$) (n=54)	Nurses feeling a higher responsibility to discuss sexual concerns ($x \geq 12$) (n=46)	Influencing Factors	Nurses feeling a lower responsibility to discuss sexual concerns ($x \leq 8$) (n=54)	Nurses feeling a higher responsibility to discuss sexual concerns ($x \geq 12$) (n=46)
Nurses have a 'responsive' role: patients have to take the first step.	Nurses feel responsible to discuss sexual concerns, but they are inhibited to take the first step.	Topic is taboo Patients and nurses are inhibited to take the first step in discussing sexual concerns.	Primarily the patients are inhibited to ask.	Patients and nurses are inhibited to ask.
Education is needed (prerequisite) to increase responsibility	Education is needed to improve the quality of care but <u>not</u> necessary	Knowledge and communication skills Lack of knowledge and skills decreased the perceived responsibility and comfort	Without any education nurses do not feel responsible discussing sexual concerns and will be silent	Nurses do not feel well prepared in discussing sexual concerns
Discussing sexual concerns with patients is <u>not</u> part of nursing	Discussing sexual concerns with patients is part of nursing	Self-concept of nursing Discussing sexual concerns is described as being part of nursing or not.	Discussing sexual concerns with patients is <u>not</u> part of nursing	(No influence)
No/low relevance of	There is a relevance	Relevance Other topics are more	No/low relevance of	This is a relevant

this topic	especially for young patients of this topic	important for patients in hospital and patients with HF have no sex anymore (age, health status, they never ask).	this topic	topic, especially for young patients , but other topics are more important in the hospital
Trust between patient and physician seems to be better.	High trust between nurses and patients	Relationship Trust, gender, and age are important aspects in a trustful relationship, which is necessary to discuss sexual concerns.	Relationship between nurses and patients regarding this topic is unequal because of different ages and gender	There is a high trust between nurses and patients, but the relationship between nurses and patients regarding this topic is unequal, because of different ages and gender
No differences		Structural barriers Lack of time, lack of privacy, and short duration of hospitalization	No differences	

Abbreviations: HF = Heart Failure