

## EMPIRICAL RESEARCH QUALITATIVE

# Women with heart failure and their experiences of sexuality and intimacy: A qualitative content analysis

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## Funding information

Bergen Hospital Trust, Norway.

## Abstract

**Aim and Objective:** This study aimed to explore how women with heart failure experience intimacy and sexual activity.

**Background:** Knowledge about women diagnosed with heart failure and their sexual activity is scarce. By investigating the experience of sexual activity and intimacy of women diagnosed with heart failure, an alignment between current practice and patients' expectations and needs within this area might be obtained.

**Design:** A qualitative design was used.

**Methods:** Fifteen women diagnosed with heart failure were recruited from a heart failure outpatient clinic at a university hospital. The study was carried out from January to September 2018. The inclusion criteria were women >18 years, with estimated New York Heart Association Class II or III living together with a partner. Face-to-face semi-structured interviews were undertaken at the hospital. The interviews were organised around a set of predetermined open-ended questions, transcribed verbatim and analysed using a qualitative content analysis. COREQ guidelines were used.

**Results:** The analysis revealed one overarching theme characterises how living with heart failure has an impact on women's sexual relationship. Furthermore, three sub-themes were identified: (1) redefining sexual activity, (2) reducing sexual activity and (3) maintaining sexual activity.

**Conclusion:** Women need information about sexual activity and heart failure in order to prevent fear and anxiety. It is important to include partners in patient consultations at heart failure outpatient clinics and in sexual counselling. It is furthermore essential to educate patients about sexual activity in relation to medication and comorbidities.

**Relevance to Clinical Practice:** Findings from this study support that information about sexuality and intimacy is a central part of the consultation in a heart failure outpatient clinic, and highlights the importance of not making assumptions about aging, frailty and interest in sexual expression.

References: Due to very limited in-depth knowledge and literature on sexuality in women with a diagnosis of HF, we felt compelled to use older references in order to shed light on the topic in a good way.

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**Patient Contribution:** Data were collected through face-to-face semi-structured interviews.

**KEYWORDS**

heart disease, quality of life, qualitative study, qualitative descriptive, qualitative approaches, sexuality, sexual well-being, women's health

**JEL CLASSIFICATION**

Advanced Nursing Practice, Adult Nursing, Cardiovascular, Heart Disease, Qualitative Study, Qualitative Approaches

## 1 | BACKGROUND

According to the World Health Organization (WHO), sexuality is an important aspect of being human, and can be expressed through love, proximity, intimacy, touch and contact with a partner (World Health Organization, 2006). Sexuality is an important factor of life satisfaction in adulthood, and life satisfaction is a key indicator of successful aging (Soysal & Smith, 2022). Sexual activity can lead to improved quality of life (QoL) by positively affecting both physical, emotional and mental health. It has been documented that a higher frequency of sexual activity is associated with a reduction in cardiovascular events later in life, a reduced risk of fatal coronary events, breast and prostate cancer, and a better self-reported QoL (Kloner et al., 2016). There are several reasons why sexual activity is beneficial for health and well-being. First, sexual activity can be considered a form of physical activity, and thus regular sexual activity is likely to provide mental and physical health benefits on a par with a physically active lifestyle (Smith et al., 2019). Second, during sexual pleasure, the release of endorphins, endogenous opioid peptides, leads to well-being (Ponzi & Dandy, 2019).

Women with cardiac disease are known to more often have sexual problems and concerns compared to women in the general population (Jaarsma et al., 2014; Küçükaya & Gönenç, 2022). They may experience other types of sexual dysfunction than men, as decline in sexual interest or desire, decline in sexual arousal, painful sexual intercourse, orgasmic disorder or vaginismus (Lucena da Silva et al., 2022). A rich sexual life has also been shown to be associated with an improved QOL and less depression among patients diagnosed with heart failure (HF) (Baert et al., 2019; Lucena da Silva et al., 2022). However, problems related to sexual activity are common among women with HF. In a non-HF population, 27% of women, aged 50–59 reported a lack of interest in sexual activity and 23% were unable to have orgasm. In comparison, 76% of women with HF reported frequent unsuccessful intercourse (Steinke, 2010). Intimacy and proximity are described as more important than sexual interaction among women after first-time myocardial infarction (Søderberg et al., 2013). As some patients experience becoming frail, with reduced functional ability and energy, sexual activity may be limited. This could reduce the patients' QOL and mental health, and affect the intimacy in their relationships (Jaarsma et al., 2014).

Health professionals have a responsibility to reassure people living with HF that, in most instances, it is safe to continue to be

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

- Women with heart failure and their partners welcome information and education about sexual activity.
- Information by health professionals about lack of sexual desire, the disease in general and the side effects of medication is crucial for the women.
- Health professionals have a responsibility to reassure people living with heart failure that, in most instances, it is safe to continue to be sexually active.

sexually active. The European Society of Cardiology (ESC) guidelines state that patients with HF are entitled to sexual counselling when needed (McDonagh et al., 2021). The American Heart Association (AHA) has stated that stable patients in New York Heart Association (NYHA) Class I or II may enjoy normal sexual activity that does not provoke undue symptoms. Sexual activity is not recommended for decompensated patients or patients classified in NYHA Class III or IV, before their condition has stabilised and is optimally managed (Levine et al., 2012).

Most patients with HF are followed up by HF outpatient clinics, and nurses in these clinics focus on patient education, psychosocial support and optimisation of medical therapy (McDonagh et al., 2021). Sexual counselling is recommended at all levels of patient follow-up (Levine et al., 2012; McDonagh et al., 2021). Nurses are responsible for providing patients with adequate knowledge of sexual activity. Patients are also entitled to receive information about the association between HF, medication and sexual dysfunctions (Levine et al., 2012).

In all, 25%–76% of women diagnosed with HF report sexual problems or concerns (Jaarsma, 2017), while 84% of male HF patients report erectile dysfunction (Wiśnicka et al., 2021). Although erectile dysfunction in men is well-recognised, knowledge about women diagnosed with HF and their sexual activity remains scarce. By investigating the experience of sexual activity and intimacy of women diagnosed with HF, an alignment between current practice and patients' expectations and needs within this area might be obtained. The aim of this study was therefore to explore how women experience intimacy and sexual activity after being diagnosed with HF.

## 2 | METHODS

### 2.1 | Design and setting

An inductive explorative and descriptive qualitative design, according to the qualitative content analysis by Graneheim and Lundman (2004), was used in order to obtain a deeper understanding of women diagnosed with HF and potential challenges relating to their sexual relationships and intimacy. A qualitative content analysis with an inductive approach is a suitable method for obtaining in-depth information about phenomena about which little is known or when knowledge is fragmented (Elo & Kyngäs, 2007). This study followed the consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups to ensure comprehensive reporting (Tong et al., 2007) (see Data S1).

The interviews took place at a separate meeting room at a university hospital.

### 2.2 | Patients and recruitment

Fifteen patients were recruited from a HF outpatient clinic. Both the first and last author included women in the study by asking them directly after a completed patient consultation. The inclusion criteria were women aged above 18 years, diagnosed with HF with estimated NYHA Class II–III and living together with a partner. Demographic and clinical data were retrieved from the patient's medical record (Table 1).

### 2.3 | Data collection

Data were collected through semi-structured interviews organised around a set of predetermined open-ended questions. These were guided based on a review of the literature within the field and the first and second authors' over four decades of clinical experience in the specific field. After analysing two pilot interviews, some minor modifications were made to the interview guide (Table 2).

The study was carried out from January to September 2018. The interviews lasted from 18 to 47 min (mean = 30.5 min) and were digitally recorded and transcribed verbatim. The first author conducted all of the interviews.

### 2.4 | Data analysis

The interviews were analysed in accordance with qualitative content analysis (Graneheim & Lundman, 2004). Qualitative content analysis comprises both descriptions of the manifest content, near the text, as well as interpretations of the latent content, distant from the text but still close to the participants' lived experience (Graneheim et al., 2017). The first author listened to the audiotapes and transcribed all interviews verbatim. The complete transcribed text constituted the unit of analysis. The first and last author analysed

TABLE 1 Selected socio-demographic and clinical characteristics of participants.

Variables	(N = 15)
Gender (female)	15
Age (years)	
40–50	3
51–60	4
61–70	3
71–80	3
81–90	2
Employed	3
Disabled	5
Retired	7
Comorbidities	
Hypertension	4
Arrhythmia	5
Kidney failure	1
Diabetes	2
Ischemic heart disease	4
Devices	
CRT-P	2
CRT-D	4
ICD	5
Duration of heart failure (years)	
1–5	6
6–10	6
11–20	1
21–30	2
NYHA classification	
Class II	13
Class III	2
Ejection fraction (%)	
20–30	6
31–40	3
41–50	5
≥51	1

Abbreviations: CRT-D, cardiac resynchronisation therapy defibrillator; CRT-P, cardiac resynchronisation therapy pacemaker; ICD, implantable cardioverter-defibrillator; NYHA, New York Heart Association.

most of the data material together. Furthermore, the second author was included in the analysis process, who is very experienced with qualitative research methods and with issues dealt with by patients with heart failure. This discussion and adjustments were iteratively done until consensus was reached. The text was condensed and labelled into meaning units presented as codes (Graneheim & Lundman, 2004). The codes were then interpreted and grouped into categories based on similarities and differences. The categories represent the visible and obvious components of the interviews, that is, the manifest content. Furthermore, sub-themes were created,

representing the latent level of the analysis process (Table 3). The latent level implies a further interpretation of the underlying meaning of the text (Graneheim & Lundman, 2004). During the analysis process, six categories were identified, resulting in three sub-themes. Finally, these were abstracted into an overarching theme that reflected the larger picture of the phenomenon (Table 3).

## 2.5 | Ethical considerations

The study follows the principles outlined in the Declaration of Helsinki (World Medical Association Declaration of Helsinki, 1964). The Regional Committee for Medical and Health Research Ethics in Western Norway approved the study (REK 2016/1261). We were not successful in recruiting potential women to the study via ordinary research measures, that is, by using information letters sent by post or inquiries by telephone. The research group experienced that women with whom they had established a relationship more often agreed to participate. The women expressed that they were confident in us and therefore wanted to participate in the study. This goes against ordinary research practice, where it is important that there is distance between researcher and patient (Polit & Beck, 2020). Nevertheless, we consider the advantages of interviewing patients with whom we had a relationship to be greater than the disadvantages, due to the sensitive topic we wanted knowledge

TABLE 2 Interview guide.

1. Thoughts about intimacy, proximity and care
  - Can you say something about the need to show each other care and proximity after the confirmed diagnosis?
  - How has it been for and your partner to resume sexual activity?
    - How did you handle this?
    - Do you miss sexual activity? If yes, how did you handle this?
2. Experiences of physical capacity related to sexual relationships and intimacy
  - Can you say something about your physical limitations? Is there a difference between good and bad periods?
  - What do you think about any physical changes?
  - Body and self-image—and intimacy; Are you experiencing change?
    - If yes, can you say something about that?
    - Can you tell us about how your partner has been affected?
3. Information and advice given by healthcare professionals
  - What do you think about the heart failure outpatient clinic approach/lack of approach to sexuality and intimacy?

TABLE 3 Examples of how quotations were used in the process of analysing the emerging themes.

Meaning unit	Condensed meaning unit	Category	Sub-theme
'I have not received information about sexuality or intimacy and heart failure from someone in the healthcare system; this has been painful and hard for me'	Missed information about sexuality after diagnosis	Need of guidance	Redefining sexual activity
'He was very soon ready to resume sexual activity, despite his fear of hurting me. That was both scary and nice'	Sexual activity was resumed very quickly, it was both scary and nice	New experiences	

about. Participation in the study was voluntary. The women were informed that they could withdraw from the study at any time, without this having consequences for further treatment and follow-up. No women withdrew from the study.

The women were assured that all information related to the interviews would be confidential and protected during the publication process. Identifiable data were stored on a secure research server at the university hospital. Only the first and second authors had access to the data.

## 3 | RESULTS

### 3.1 | The overarching theme: Living with HF makes an impact on women's sexual relationship with their partner

The overarching theme characterises how living with HF has an impact on women's sexual relationship with their partner. In the first sub-theme, the women described a significant need for information about sexual activity and both the women and their partners found the absence of information about sexual activity frustrating. During periods where sexual activity was reduced, it was even more important to show each other proximity and find alternative ways of sharing intimacy. In the second sub-theme, the women described reduced sexual activity due to exacerbation of HF and medication adjustments. Furthermore, partner's fear of acute deterioration of HF symptoms and how they protect their partner were described. In the third sub-theme, the women described how they found it important to find other ways to maintain sexual activity and have a positive attitude to life. The three sub-themes and associated categories are presented consecutively.

#### 3.1.1 | Sub-theme 1: Redefining sexual activity

*Need of guidance:* The women stated that they had not received information about sexual activity when discharged from hospital, at the HF outpatient clinic or from their general practitioner (GP). 'When I tried to ask the GP when I could reassume sexual activity, the GP asked if I knew how old and ill I was. I was so furious and frustrated that I became depressed. The health service should be able to answer that kind of question' (Woman, 73 years old). The women highlighted

their need for information and advice on alternative ways of having intercourse. In the absence of relevant information from the health-care services, they had searched for information on the internet. Some had also read brochures they had been given at the hospital. They pointed out that they assumed information on intimacy and sexual activity would be a natural and important part of patient follow-up. 'I believe in more openness about sexuality and intimacy. Tell us about it when you inform us about new medication, be honest with patients and take the time to tell them. Tell them about possible side effects of medication and provide sexual advice' (Woman, 40years old). Some women felt that both they and their partners had received insufficient information about implantable cardioverter-defibrillators (ICD) and sexual activity. The resumption of sexual activity was associated with both fear and insecurity. 'When I had received the ICD, I asked how long I had to wait before I resumed sexual activity. We were worried about whether it would be dangerous or not for him if I got a shock during intercourse. When I got the information, I felt secure and then it worked out well' (Woman, 50years old).

*New experiences:* During periods where sexual activity was limited, the women found it even more important to show each other proximity in terms of hugs and care. 'We have a very close relationship, but there has been no focus on sexual activity. We often give hugs and show proximity' (Woman, 62years old). The partners often showed care in the form of practical tasks to ease the women's everyday life. If sexual activity was difficult due to disability in both the women and their partner, they found alternative ways of sharing intimacy. 'It has not been a problem – we find other solutions together. He has always been a loving man' (Woman, 66years old). Both the women and their partners were aware of the risk for exacerbations the first time they had sexual activity after a confirmed HF diagnosis. Some women stated that they still had resumed sexual activity shortly after being diagnosed. At this time, they described their sexual intercourse as both scary and beautiful at the same time. 'He was very soon ready to resume sexual activity, despite his fear of hurting me. That was both scary and nice' (Woman, 50years old).

### 3.1.2 | Sub-theme 2: Reducing sexual intimacy

*Increased symptom burden:* For some women, the exacerbation of HF and medication adjustments resulted in reduced sexual activity for a prolonged period. The use of diuretics often led to interrupted sleep, tiredness and reduced the capacity to enjoy sexual activity. Furthermore, they reported that some medication caused changes in body odour. 'Every time I got new medication, I experienced an unpleasant body odour that I didn't like – it felt nasty. Every time my husband approached me, I rejected him. I didn't want him to smell this unpleasant body odour' (Woman, 66years old). The women's increased experience of dyspnoea and frailty made them feel uncomfortable in their sexual relationship. Bodily changes and weight gain also played a pivotal role in achieving sexual satisfaction. The women found it difficult to distinguish between menopause and symptoms related to HF. They described feeling that neither their

body nor their mind was ready for sexual activity, despite having a sexual desire. Experiencing dry mucous membranes and discomfort during sexual intercourse also reduced their desire for an active sexual life. 'It's not that I don't want to. We have tried sometimes, but then it's been like I've felt dry and that neither my body nor my mind has been ready for it. Therefore, sexual activity has been reduced' (Woman, 62years old).

*Impact on proximity and relationship:* Some women experienced that their partner had an increased need to know that they were feeling well in social contexts and activities due to fear of acute deterioration of HF symptoms. The women's partners could also take action to protect them. 'All sexual activity ceased on the day the diagnosis was confirmed, because he was afraid of worsening my HF condition' (Woman, 72years old). The longing for sexual activity could still be great, despite them agreeing that it had ceased. 'During some periods, I miss the sexual relationship very much, and so does he. This is therefore a mutual experience' (Women, 83years old). Symptoms of multiple chronic diagnoses contributed to ending sexual activity. Changed needs in relation to sexual activity due to comorbidities and increasing age was an aspect also highlighted in the interviews. 'I'm not going to try again. After surgery, the breast cancer and pulmonary embolism, it became too much. We agreed that it has ended; it's not worth trying anymore' (Woman, 86years old).

### 3.1.3 | Sub-theme 3: Maintaining sexual activity

*Change of perspective:* The women felt that they could not be as spontaneous as before. They had to schedule physical and sexual activity when they were rested. Some women found this stressful. 'I felt very inadequate due to physical limitations, as I could not have sexual activity when I really wanted to' (Woman, 50years old). This mutual experience led to them attempting new positions and having sex in different ways. The women described feeling an increased passion in the intimate. 'You can have sex in many ways. You don't need to be an athlete to have good sex; there are many ways to do it' (Woman, 55years old).

*Positive attitude to life:* The women and their partners decided to live life to the fullest. They highlighted the value of maintaining a normal sex life without fear and limitations. 'I decided to live as usual, also sexually, without fear and limitations. We do everything and I enjoy our sex life' (Woman, 73years old). Some women and their partners shared the notion that the risk of death during sexual activity was likely to be low. They stated that they had never thought they were going to die during intercourse. Some of the women had nonetheless experienced acute incidents during sexual activity. 'I had sex, and suddenly I couldn't breathe... fortunately, it took a short time before the ambulance arrived... because then I had an acute pulmonary oedema... and there were no warning signals' (Woman, 55years old). Despite adverse events, they stated that these experiences did not prevent them from enjoying sexual activity. The women also felt that their partners were not afraid to resume sexual activity after such incidents, as long as they felt ready for it themselves.

## 4 | DISCUSSION

This is the first study to describe how women diagnosed with heart failure experience their sexuality and intimacy. Despite HF, low ejection fraction (EF) and implanted devices, the women were focused on maintaining intimacy and sexual activity. The women stated that they had assumed information about intimacy and sexual activity would be a natural and important part of patient follow-up. They experienced both increased symptom burden and physical limitations, which in turn caused reduced sexual activity. Some women also felt that their sexual activity was satisfactory, even after being diagnosed with HF, as they changed their perspective and maintained a positive attitude.

Healthcare professionals often fail to address, discuss and provide information about sexuality and intimacy to both sexes (Baert et al., 2020; Hoekstra et al., 2012). The women in this study had expected healthcare professionals to inform them when or how to reassume sexual activity, despite HF deterioration, ICD implantation or high age. This corresponds with previous findings, where 39% of healthcare professionals avoided discussing sexual activity with patients they considered to be too old or too frail to enjoy such activities (Hoekstra et al., 2012). Despite clear recommendations and advice, healthcare professionals rarely discuss this topic with their patients (Baert et al., 2020; Jaarsma et al., 2014). Overall, 75% of women and 60% of men with HF have never discussed sexuality and the importance of intimacy with a healthcare professional. The barriers preventing healthcare professionals from promoting knowledge of sexuality and intimacy include a lack of organisational policy, ignorance of how to introduce the topic and a lack of experience (Hoekstra et al., 2012; Wiśnicka et al., 2021). These findings highlight the importance of healthcare professionals' proactive role in the assessment of sexual problems in women with HF, and thereby contribute to improving the QOL of both the women and their partners.

It is important that healthcare professionals also inform women with implantable cardioverter-defibrillators (ICD), cardiac resynchronisation therapy pacemaker (CRT-P) and cardiac resynchronisation therapy defibrillator (CRT-D) about sexual activity. The women in our study felt that both they and their partners had received insufficient information about ICD and sexual activity. Sexual activity is reasonable for stable patients with an ICD or CRT-P/D. The women should be informed that sexual activity should be paused if they experience uncontrollable or exertion-induced ventricular tachycardia until the causative arrhythmia has been stabilised and optimally treated (Levine et al., 2012).

The women in our study experienced acute pulmonary oedema during sexual intercourse without any warning signals or signs of deterioration. Despite this, the women stated that they continued to enjoy sexual activity. Most patients in NYHA Class I or II should be able to enjoy normal sexual activity without provoking undue symptoms (Levine et al., 2012; McDonagh et al., 2021). However, sexual intercourse is not recommended for patients classified in NYHA Class III or IV, until their physical condition has stabilised (Levine et al., 2012). HF patients who have decreased exercise tolerance might

enjoy alternative sexual activities to sexual intercourse. Patients with chronic HF can alternate between NYHA classes throughout the disease, which may be challenging when advice and recommendations are warranted (McDonagh et al., 2021). Inadequate information from healthcare professionals could therefore result in inconsistent recommendations regarding NYHA classes and sexual activity.

Several types of HF medication can have an effect on sexual performance and desire in both women and men, although new generations of medication appear to have less sexual side effects (Jaarsma et al., 2014). In our study, the women stated that they had not received information about the link between HF medication and sexual activity. The women struggled to distinguish between a lack of sexual desire, the disease in general and the side effects of medication. It is therefore crucial to inform the women of the necessity and benefits of their medication. Optimal medical treatment is important to increase sexual performance in patients diagnosed with HF (McDonagh et al., 2021).

Some women experienced an unpleasant body odour when starting on new HF medication, which in turn reduced their regular sexual activity. These women felt uncomfortable with intimacy and sexual activity due to the unfamiliar bodily changes. Altered body odour is not reported as a side effect of the most commonly used heart failure medication. Side effects, particularly those that are rare, are often underreported (Seruga et al., 2016). Furthermore, it is well known that diuretics have both beneficial and unfavourable effects. Women may experience reduced vaginal lubrication and irregular menstruation related to aldosterone antagonists and thiazides (McDonagh et al., 2021). In a previous study, 80% of women with HF reported reduced vaginal lubrication (Steinke, 2010). The women in our study found it difficult to distinguish between menopause, the side effects of diuretic medication and exacerbation of the disease. They felt that diuretics contributed to interrupted sleep and tiredness, and thereby a reduced ability to enjoy sexual activity.

Furthermore, they expressed that intimacy and proximity were important to their perceived QOL. There was increased passion in the intimate and the patients highlighted that it was both scary and beautiful at the same time to resume sexual activity. Furthermore, they expressed that they maintained normal sexual activity even after confirmed HF, because they had decided to do so. The women also experienced that their partners were not afraid to resume sexual activity, as long as they were ready for it themselves. Correspondingly, patients afflicted with a chronic cardiac disease report increased closeness both sexually and emotionally (Dalteg et al., 2011). These findings indicate the importance of healthcare professionals' proactive role in the assessment of potential sexual problems in women with HF, and can thereby contribute to improving the QOL of both women and their partners.

## 5 | LIMITATIONS

This is the first qualitative study to describe how women diagnosed with HF experience their sexuality and intimacy. However, the study

has three limitations that need to be considered. First, the women were recruited only from one centre. Second, due to the potentially sensitive topic, only 15 patients agreed to participate, which was deemed sufficient for the qualitative analysis of this study as the interview data were rich and broad. Third, the credibility of the data may have been affected by the fact that we interviewed patients for whom we had treatment responsibility, as the women may have shared more than they really wanted, in order to meet researchers' and practitioners' needs for information (Polit & Beck, 2020).

## 6 | CONCLUSION

The women need information about sexual activity and HF to prevent potential fear and anxiety. Patient education in sexuality and intimacy must be accurate and to the point. Furthermore, it is important to include partners in patient consultations and sexual counselling at HF outpatient clinics. Information relating to medication and comorbidities is essential. Further studies on women diagnosed with HF related to sexuality and intimacy are warranted, as well as studies regarding partners' experiences of living with a woman diagnosed with HF.

## 7 | RELEVANCE TO CLINICAL PRACTICE

Findings from this study support that information about sexuality and intimacy is a central part of the consultation in a heart failure outpatient clinic. Women with heart failure of all ages highlight the need for intimacy and proximity, and it is important that healthcare professionals do not make assumptions about aging, frailty, and interest in sexual expression. This assumes that nurses in heart failure outpatient clinics and GPs increase their expertise in heart failure and sexual counselling.

### FUNDING INFORMATION

This work was supported by a grant from Bergen Hospital Trust, Norway.

### CONFLICT OF INTEREST STATEMENT

The authors have no conflict of interest to declare.

### DATA AVAILABILITY STATEMENT

The dataset generated and analysed is not available for others according to Norwegian data protection legislation. Analysis files can be made publicly available from the corresponding author on reasonable request.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Markhus, L. S., Mårtensson, J., Keilegavlen, H., & Fållun, N. (2023). Women with heart failure and their experiences of sexuality and intimacy: A qualitative content analysis. *Journal of Clinical Nursing*, *32*, 7382–7389. <https://doi.org/10.1111/jocn.16775>