

Provided by the author(s) and University of Galway in accordance with publisher policies. Please cite the published version when available.

Title	Participants' experiences of a sexual counseling intervention during cardiac rehabilitation: A nested qualitative study within the CHARMS pilot randomized controlled trial
Author(s)	D'Eath, Maureen; Byrne, Molly; Murphy, Patrick; Jaarsma, Tiny; McSharry, Jenny; Casey, Dympna; Murphy, Andrew W.; Doherty, Sally; Noone, Chris; Casey, Dympna
Publication Date	2018-09-01
Publication Information	D'Eath, Maureen, Byrne, Molly, Murphy, Patrick, Jaarsma, Tiny, McSharry, Jenny, Murphy, Andrew W., Doherty, Sally, Noone, Chris, Casey, Dympna. (2018). Participants' Experiences of a Sexual Counseling Intervention During Cardiac Rehabilitation: A Nested Qualitative Study Within the CHARMS Pilot Randomized Controlled Trial. Journal of Cardiovascular Nursing, 33(5), E35-E45. doi: 10.1097/jcn.0000000000000482
Publisher	Lippincott, Williams & Wilkins
Link to publisher's version	https://dx.doi.org/10.1097/JCN.0000000000000482
Item record	http://hdl.handle.net/10379/15187
DOI	http://dx.doi.org/10.1097/JCN.0000000000000482

Downloaded 2024-05-24T02:36:03Z

Some rights reserved. For more information, please see the item record link above.



Participants' experiences of a sexual counselling intervention during cardiac rehabilitation: a nested qualitative study within the CHARMS pilot RCT

Authors: Maureen D'Eath ¹; Molly Byrne¹; Patrick Murphy²; Jenny McSharry¹; Tiny Jaarsma; Andrew Murphy⁴; Sally Doherty⁵; Chris Noone¹; Dympna Casey⁶.

Author Affiliations

Maureen D'Eath (MSc)¹; Molly Byrne (PhD)¹; Patrick Murphy (PhD)²; Tiny Jaarsma (PhD)³; Jenny Mc Sharry (PhD)¹; Andrew W Murphy (MD)⁴; Sally Doherty (PhD)⁵; Chris Noone (PhD)¹; Dympna Casey (PhD)⁶.

1. Health Behaviour Change Research Group, School of Psychology, National University of Ireland, Galway, Ireland.
2. Disciplines of Occupational Therapy and Radiation Therapy, School of Medicine, Trinity College Dublin, Ireland.
3. Department of Nursing, Linköping University, Sweden
4. Discipline of General Practice, National University of Ireland, Galway, Ireland
5. Department of Psychology, Royal College of Surgeons in Ireland, Dublin, Ireland.
6. School of Nursing, National University of Ireland, Galway, Ireland.

Corresponding Author

Maureen D'Eath, Health Behaviour Change Research Group, School of Psychology, National University of Ireland, Galway, Ireland. Phone: +353-91-49-4455.

Email: maureen.death@nuigalway.ie

Abstract

Background

International guidelines recommend sexual assessment and counselling be offered to all patients with cardiovascular disease during cardiac rehabilitation. However, sexual problems are infrequently addressed. The Cardiac Health and Relationship Management and Sexuality (CHARMS) intervention is a complex, multilevel intervention designed to increase the provision of sexual counselling in cardiac rehabilitation. It was piloted in two cardiac rehabilitation centres to assess the acceptability and feasibility of the intervention and to inform and refine a definitive cluster RCT protocol.

Objectives To explore the experiences, perceptions and opinions of patients, partners and cardiac rehabilitation staff who participated in the CHARMS staff-led patient-education class.

Methods A qualitative descriptive study employing semi-structured interviews was used to collect the data. Cardiac rehabilitation staff (n=8) were interviewed when the intervention commenced in their centre and three months later (n=6). Patients (n=19) and partners (n=2) were interviewed following delivery of the class; 7 were interviewed again 3 months post-intervention to explore temporal changes in opinions.

Results Most cardiac rehabilitation staff were comfortable delivering the CHARMS intervention but would prefer a less structured format. Some staff perceived discomfort among patients. Few patients reported discomfort. Most patients and partners considered that the intervention was a welcome and acceptable part of a cardiac rehabilitation programme.

Conclusions

Incorporating sexual counselling into cardiac rehabilitation programmes is feasible. Although the views of the patients and staff diverged on a number of issues including the perceived comfort of patients, its inclusion was welcomed by patients and was acceptable overall to both staff and patients.

Keywords: Cardiovascular diseases; cardiac rehabilitation; sexual assessment and counselling; sexual dysfunction; qualitative

Background

This paper documents the experiences of patients, partners and cardiac rehabilitation staff who participated in the Cardiac Health and Relationship Management and Sexuality (CHARMS) intervention pilot study. The CHARMS intervention aims to improve sexuality-related outcomes for patients with heart disease through increasing the provision of sexual assessment and counselling in hospital-based cardiac rehabilitation programmes by cardiac rehabilitation staff.

Patients with cardiovascular disease are more likely to experience sexual problems compared to the general population. Sexual problems can negatively impact the well-being and quality of life of patients [1]. Furthermore, partners may experience anxiety or fear as a result of the patient's cardiac condition; sexual concerns are among the most common stressors reported by partners of people with cardiovascular disease [2, 3].

Sexual counselling provides information, reassurance and guidance to patients and partners to allay concerns and support a safe return to sexual activity [4, 5]. Patients have expressed a need and a desire for sexual counselling [6] and international guidelines support the provision of such counselling to both patients and their partners [2]. Despite this expressed patient need, sexual health problems are rarely addressed during cardiac rehabilitation [7]. Two key reasons for this have been identified: firstly, the personal and sensitive nature of the topic which prohibits patients from raising the issue [8] and secondly, the unpreparedness of health professionals in terms of lack of training, knowledge, comfort and skills to confidently discuss sexual health problems with their cardiac patients [9, 10].

The CHARMS baseline study was undertaken in 2013 and examined the prevalence and treatment of sexual problems among patients attending cardiac rehabilitation in Ireland [11]. Forty-seven per cent of the 382 patients surveyed reported no sexual relations in the previous year and nearly a half of sexually active respondents reported at least one sexual problem. The study also found, consistent with previous literature, that sexual problems were infrequently addressed during cardiac rehabilitation or in other healthcare contexts for reasons such as lack of education, training and

confidence on the part of healthcare professionals [12, 13]. However patients reported that they would welcome information and wanted the issue of sexuality to be addressed in an explicit way throughout and after the rehabilitation process by confident and knowledgeable professionals [14].

Following the CHARMS baseline study, Byrne et al developed the CHARMS intervention [15]. The aim of the intervention is to improve sexuality-related outcomes for patients with heart disease through increasing the provision of sexual assessment and counselling by staff in hospital-based cardiac rehabilitation programmes. This is a complex, multilevel intervention targeting both staff and patients, the details of which are described elsewhere [15, 16]. In brief, this intervention includes: a) training and support for cardiac rehabilitation staff, b) a 30 minute staff-led patient education class about sexuality and cardiac disease c) a patient information booklet and d) an awareness raising poster.

In compliance with guidance from the Medical Research Council [17], the CHARMS intervention was piloted in 2016/17 to assess its acceptability and feasibility and to inform and refine the planned roll-out of the intervention in a definitive cluster randomised control trial (RCT). The details of the pilot study protocol are published elsewhere [15]. The added value of incorporating qualitative methods into pilot and feasibility studies, and RCTs is increasingly recognised [18-21]. Utilising qualitative methods with pilot or full RCTs enables researchers to capture a more in-depth understanding of the views and experiences of key stakeholders to evaluate the feasibility and acceptability of the intervention, improve the design of future trials [18, 21] and enhance understanding and interpretation of overall trial findings [22]. In the context of this study a qualitative descriptive approach was utilised to provide a more in-depth understanding of the perceptions and experiences of the key stakeholders, namely patients, partners and cardiac rehabilitation staff, of participating in the CHARMS intervention and their views as to the feasibility and acceptability of the intervention to inform the future definitive RCT. This paper presents the findings from the results of this qualitative component of the CHARMS pilot study.

Setting

The pilot study took place in two cardiac rehabilitation centres in Ireland which provide Phase 3 cardiac rehabilitation. Phase 3 cardiac rehabilitation typically starts 4-6 weeks post-discharge from acute care, lasts between 6-8 weeks and involves twice-weekly supervised exercise and group-based educational sessions on various topics related to living with cardiovascular disease. Information about sexuality and cardiac disease was provided as part of the cardiac rehabilitation programme in one of the participating centres (Centre 1) and was not routinely addressed in the other centre (Centre 2). Staff from the two cardiac rehabilitation centres were invited to attend a two hour training intervention programme in sexual counselling. An experienced cardiac rehabilitator, recruited specifically for the study, delivered the training programme which included (1) introducing the rationale for the CHARMS intervention and then (2) introducing international sexual counselling guidelines; (3) the practice of sexual counselling skills; (4) details of the CHARMS patient intervention (5) how to implement a plan for the CHARMS patient intervention, and addressing identified barriers to implementation; finally there was an opportunity for questions and answers. Following completion of the training, staff delivered the CHARMS patient intervention: a dedicated 30 minute education class within the existing cardiac rehabilitation programme presented through PowerPoint.

Recruitment

Participants in the qualitative study comprised cardiac rehabilitation staff, patients attending cardiac rehabilitation and partners of patients. All nine members of the participating cardiac rehabilitation teams who received training on the CHARMS intervention were included in the study and invited to participate in the qualitative interviews; no exclusion criteria were applied. The six staff members who delivered the CHARMS patient education class were invited to participate in a second interview three months later. All patients who consented to participate in the CHARMS study and who returned a completed survey were included and invited to participate in the qualitative study no exclusion criteria were applied. Patients whose partners returned a questionnaire were asked whether their partner would consider taking part in an interview and for contact details for that partner. Patients and

partners who took part in the interviews were asked for permission to contact them again at a later date for a follow-up interview.

Qualitative Methodology

A descriptive qualitative approach based on the work of Sandelowski (2000) [23] guided the current study. This qualitative approach enables the researcher to stay close to the data facilitating the production of a rich description of participants' experiences [24]. The first staff interviews took place at a point at which those involved in the delivery of the patient education class had delivered it on at least one occasion. All first interviews were individual, face-to-face interviews and took place in the cardiac rehabilitation centres. The development of the semi-structured interview guides were based on the aims of the qualitative study, namely to explore the feasibility and acceptability of the intervention as well as the participants' overall experiences of participating in the intervention. The interview guides for the staff and the patients/partners were developed to reflect each other and examples of the questions are presented in Table 1 below:

Table 1: Sample questions

Staff sample questions	Patient sample questions
How did you feel about your centre becoming involved in the CHARMS pilot study?	How did you feel when you were invited to become involved in the CHARMS study?
Regarding the content of the CHARMS	

programme: What worked well? What didn't work well?	Tell me about the content of the class?
What was the response of the group to the class? Did it vary between the groups?	Did it work well as a group session? How was it received by the group?
Did partners attend the session? Why do you think that was?	Did your partner attend? Why/Why not?
To what extent would the programme be an acceptable/feasible/worthwhile addition to the cardiac rehabilitation programme on a permanent basis?	How acceptable/feasible/worthwhile was it for you to receive the CHARMS programme as part of your 8 week rehabilitation programme?

Staff members involved in the delivery of the patient education class were invited to take part in a second interviews. The second interviews took place a minimum of three months after the first interviews and after completion of the delivery of the intervention. The semi-structured interview guides for the second interviews were, in the main, individually developed to further probe opinions given during the first interviews. The focus of these interviews was to explore more deeply their experience of participating in the CHARMS pilot intervention and to reflect, through the prism of

their experience of the intervention, on comments that they had made during their first interview. Four of the second interviews took place face-to-face and two were conducted by telephone.

Patients were invited by letter to participate in the qualitative interviews. The letter informed the participants that a researcher would telephone them on a specified date unless they phoned or emailed to request no further contact. Partners were contacted using the contact details provided by the

patients. Patient interviews were also undertaken at two time-points using semi-structured interview guides. These interviews were completed approximately two weeks after the delivery of the patient education class within the patients' cardiac rehabilitation programme. Interviews took place at a time and place that suited participants. Most of the first patient interviews, and one of the partner interviews, took place in a private office in the cardiac rehabilitation centres, one took place in a hotel and one patient and partner dyad interview took place in their home. The second patient interviews sought to explore any temporal changes in their perspectives of the CHARMS intervention. All second patient interviews were telephone interviews. Interviews were conducted by an experienced qualitative researcher (MD).

Data Analysis

Interviews were audio-recorded and professionally transcribed. Transcripts were imported into Nvivo [25] to facilitate data organisation, management and analysis. In keeping with a descriptive qualitative approach, qualitative content analysis was used to analyse the data. Following a process outlined by Hsieh and Shannon (2005) [26] the transcripts were initially read several times to become familiar with the data; open codes were initially used and then the interview guides were used as a framework for structuring the open coding. The codes were sorted into related and linked categories which were, in turn, collapsed under larger categories. The analysis was conducted by one researcher (MD); a second researcher, (DC), read all the transcripts and verified the coding and analysis. The rigour of the research was enhanced through this involvement of two researchers in the coding and analysis and also by maintaining a clear audit trail detailing the research strategy, data analysis and findings [27, 28].

Results

Eight of the nine staff members who received the CHARMS training took part in the first interviews; one staff member was aware that they would not be involved in the delivery of the patient education class and therefore did not participate in a first interview. Six of the eight staff members who took part in the first interviews were involved with the CHARMS intervention for the duration of the pilot study and these six staff took part in the second interviews. The staff members came from a range of healthcare professions including nursing, social work and occupational therapy.

Successful telephone contact was made with 37 out of 42 patients who returned the CHARMS survey questionnaire and 19 agreed to be interviewed. Nine patient interviews took place over the telephone and ten were face-to-face. The length of the interviews varied between 8 and 78 minutes (mean 40 minutes). Ten participants gave consent to be contacted again with an invitation to participate in a follow up interview. Seven were successfully contacted again a minimum of three months after the first interview to explore changes in their opinions and experiences over time; the other three did not agree to a further interview as they did not feel that they had further information to contribute.

Two partners of patients participating in the CHARMS intervention agreed to take part in an interview; one took part in a joint interview with her partner and the other took part in a one-to-one interview. Most patients were not inclined to involve their partners in the study; most commonly they stated that their partner would not be interested or would not 'be bothered'.

The characteristics of the participants are presented in Table 2:

Table 2: Participant Characteristic

	Centre 1	Centre 2
Staff Time 1 interviews	n=4	n=4
Staff Time 2 interviews	n=4	n=2

Patient Time 1 interviews	9 males	8 male; 2 female
	age range 52-76;	age range 43-78;
	mean age: 61	mean age: 58.6
Partner Time 1 interviews	0	2 female
		ages: 43 & 63
Patient Time 2 interviews	4 males	1 male; 2 females

The data is presented by stakeholder group – staff followed by patients and partners - and under three themes. A description of these three themes is presented in Table 3 below:

Table 3: Themes

Theme 1: <i>Getting involved</i>	This describes participants' reasons for taking part in the CHARMS study and any concerns they had prior to their involvement
Theme 2: <i>Experiences of the CHARMS Patient Education Class</i>	This describes the perspectives of those involved in delivering the class and those who received the class. Included under this theme are views about

	the content and timing of the class, the use of Powerpoint as a vehicle to deliver information about sexuality, the response of the group to the class, the involvement of partners and the issue of follow-up consultations.
Theme 3: <i>Reflections</i>	This themes describes the impact which the CHARMS patient education class was perceived to have had on staff and on patients and presents the participants' views on the feasibility and acceptability of incorporating the CHARMS patient education class into cardiac rehabilitation programmes.

The findings from the staff, and patients who took part in the two rounds of interviews remained consistent across the interviews with no changes of view over time identified. Therefore, the data is presented without reference to the time point of the interviews.

Staff Findings

Theme 1: Getting Involved

Generally staff welcomed the involvement of their centre in the CHARMS study. Many were aware of CHARMS from the baseline study, some were interested in the research and staff in one centre welcomed the introduction of a new component into the existing cardiac rehabilitation programme. Involvement in the CHARMS pilot study was also seen as offering the opportunity to address a topic which some staff perceived as not being fully addressed in cardiac rehabilitation or, indeed, within the hospital generally. However, despite the general welcome for the intervention, some staff were apprehensive and concerned that it might upset patients or make patients so uncomfortable that they would withdraw from the entire rehabilitation programme,

But to be giving this very sensitive information ... I was dubious as to how well it would be received. (Centre2HP4)

I think sometimes raising things with groups, people can be particularly uncomfortable around it [sexual health]. And I think there has been some concern that maybe it might put people off coming into the sessions. That it can be quite off-putting. (Centre1HP2)

Theme 2: Experiences of the CHARMS patient education class

The number of staff who delivered the CHARMS patient education class differed between the two centres. In Centre 1, two members of the team delivered the intervention twice, one member delivered it three times and the fourth member was available to patients and partners for follow-up consultations including issues related to sexual health. In Centre 2, a single member of the cardiac rehabilitation team delivered the class, delivering a total of 14 classes; a second member of the team was available for follow-up consultations. The centres also differed in the lead-up to the class. In Centre 2 the CHARMS patient education class was listed under the “Return to Activities” in the timetable given to patients at the start of their cardiac rehabilitation programme and staff did not expand on the content of the class. In Centre 1 the class was listed as “Resuming Sexual Activity” and staff reminded patients about the topic to be addressed prior to the class. Staff in this centre encouraged patients to attend their exercise class on that day and then choose whether or not they wished to stay and attend the CHARMS class. Some staff in Centre 1 reported that patients had opted out of the CHARMS class,

*Some people came to me and said they're not interested and they were leaving. They didn't wait for it. And that would have happened in every group. **They chose not to come?** Yea, they chose not to come (Centre1HP1)*

However, it was also reported that attendance rates at cardiac rehabilitation programmes varied for a range of reasons including work or family commitments, illness or holidays and therefore it was

difficult to know whether CHARMS impacted on attendance. Both centres positioned the CHARMS patient education class towards the end of the rehabilitation programme allowing group members and staff time to get to know each other or get comfortable with each other,

The group I knew well. ... If this would be a six-week programme they were in to the end of their fifth week –so they knew me and I knew them. I think that made it much easier. It made, you know, it did make a huge difference, I felt (Centre1HP4)

Some reservations were expressed about the standardised CHARMS PowerPoint presentation used to deliver the patient education class which was considered by most staff members to be quite long and repetitive with slides containing more text and less images than they would usually use in a PowerPoint presentation. Some considered it a barrier to the flow of interactions within the group turning the class into a lecture rather than a discussion,

If I'm giving the talk on risk factors, we'll say, I have slides done up, they are mostly photographs and pictures that I talk around. I know that sounds a little bit, like I'm saying they are not capable of understanding but I know it holds their interest more. Plus it allows me to tailor it to the audience ...I'll skip through the ones I think are more relevant. And it really creates a more discussion type than a lecture. I just think that has more of an effect on them. (Centre1HP3)

In response, some staff reported amending the presentation to suit their own delivery style while retaining the core message. These changes included reorganising slide sequence, reducing slides whilst still retaining all the information, and including a film clip.

Staff had little difficulty overall with the content of the educational presentation. However, a concern was raised about the content on Hormone Replacement Therapy and the relative benefits of topical oestrogens; it was suggested that this issue was too complex to reduce to advice on a PowerPoint slide. In addition a number of staff found the slide which focused on the topic of vaginal dryness

problematic. They reported that this information was difficult to deliver due to their own embarrassment or the perceived discomfort this might cause to a mixed gender group,

...maybe it's me that was uncomfortable just saying it, I can't remember it now like women and lubrication and talking it out like that. Just sounds so, I don't know what the word is, stark or something. ... I would have said women could have some difficulties after menopause and I would have left that to their imagination. I suppose because I know from saying that as a healthcare professional I know it makes some of the women, there was only two women in the group of men, and they can make the men embarrassed never mind the women embarrassed. (Centre1HP3)

Overall however, although some staff members perceived some discomfort on the part of the patients, *My instinct tells me that they were very uncomfortable (Centre1HP3)*, most reported that the class was well-received and several spoke of a light-hearted response within the class

The talk has gone down very well. It's been actually quite easy with a good few laughs here and there, you know. (Centre2HP3)

Nonetheless, many of the cardiac rehabilitators reported that the CHARMS patient education class lacked the interaction that is a feature of classes within cardiac rehabilitation as they felt that the presentation stimulated little discussion. They also reported that the presentation prompted few questions and those that were asked were mainly about medications.

In line with international guidelines, staff were asked to extend a specific invitation to partners to attend the CHARMS class, however none reported that they did so. Staff described that partners rarely attended any of the classes in the cardiac rehabilitation programme that were open to them; just one partner attended the CHARMS class and she attended most of her husband's rehabilitation classes. Staff suggested that patients would be reluctant to include their partner in a class focussing on

sexuality in case it would lead to the unwelcome interpretation by others that a couple were experiencing sexual difficulties,

But I think people are very aware that if they brought a partner in that it would look like they were putting up a red flag saying, yes, you know, we're attending this talk because there's something wrong here. So it'll look very conspicuous. (Centre1HP2)

Staff were also asked to encourage patients to talk with a member of the cardiac rehabilitation team if they had further questions or concerns about sexual problems following the CHARMS patient education class. Staff in both centres reported a reduction in patients approaching them with sexual queries with only one patient availing of the invitation to follow-up.

Theme 3: Reflections

Reflecting on their experiences of the CHARMS intervention many cardiac rehabilitators recounted the impact the programme had on their practice in terms of raising awareness and prioritising sexuality and intimacy as an issue. Others felt that their involvement in the intervention gave them the opportunity to examine their own preconceptions and unease about raising the issue with some patients,

And I suppose partly about looking at my own assumptions. Like one of them was widowed and yea trying to look at my own perceptions and expectations and assumptions and say am I right to actually not be asking people questions. Or is it more my discomfort that's giving me an opt out. (C1CR2)

The most commonly cited benefit which staff members considered might accrue to the patients was that of awareness. CHARMS was also seen as an acknowledgement and normalising of the issue of sexual problems which might empower some patients to address further in their own way and in their own time.

I think even by raising it, it basically gives people the chance to consider whether or not they want to respond. ... I think it does give people a sense of, okay it's not just me.... . Even if it may not be one of their priorities at the moment. Or it might not be something they feel comfortable talking to us about. But maybe in time to come it might more of an issue they'll want to look at. And hopefully if they don't talk to us about it they might talk to the GP, or another professional. (C1CR2)

Likewise it was felt that the CHARMS intervention was a support to patients, particularly older patients, as it provided them with the language to discuss the topic should they wish to in the future

... now people have the language, because a lot of elderly people may not have had the language ... And at least they have the language now, and that they know it can be broached in a constructive manner. And they know it can be brought up with the doctor or a nurse again at some stage, and I think that is very good to give them – it is a good thing to have it covered, (C1CR4)

All staff agreed that sexual counselling was an appropriate topic in cardiac rehabilitation programmes. Staff in Centre 2 strongly supported the content and format of the CHARMS class and are committed to including it as a permanent component of their cardiac rehabilitation programme in the future,

It is something I am going to keep going. ... I probably may not change it that much but the information is good, it goes across to the patients well and I'm definitely going to continue with it. And I think us, as a team, we all agree that it was a very worthwhile thing to be involved with and that it is something we should continue with (Centre2HP5)

However, staff in Centre 1 were more circumspect about the inclusion of the patient education class. Most reported that a once-off class on sexual health was insufficient and felt that the topic should be integrated during the entire rehabilitation programme. They also reported that sexuality was addressed

in their cardiac rehabilitation programme prior to CHARMS although in a less formal, structured way and, for most, that approach was preferable,

I still have a big question mark over it and at the moment I'm kind of against the whole sit-down, I'm going to tell you all about sex in a didactic way. It doesn't sit well with me but I don't think, I think it makes me uncomfortable, that's my own way of thinking. It's out of kilter with the rest of the program to be honest. (Centre1HP3)

Patients Findings

In the next section the findings from the patient data will be presented under similar thematic headings as that of the staff data

Theme 1: Getting involved

Patients reported that they chose to 'get involved' and participate in the CHARMS study for altruistic reasons in the belief that their involvement "*might be useful, beneficial to someone maybe*" (Centre2Patient23); or because of a sense of gratitude or debt to health services; or an interest in research or the generation of knowledge. Although almost one third of patients spoke of getting involved because they were experiencing sexual problems, most patients and their partners, including those who were experiencing sexual difficulty, reported that they had been unaware of the connection between sexual function and cardiovascular issues,

That they [cardiac patients] can have problems after a cardiac arrest which frankly is something that I would never have thought of. It wouldn't have occurred to me.
(Centre1Patient13)

Theme 2: Experiences of the CHARMS patient education class

Most patients tended to view the educational class as simply one of the many classes which they attended during cardiac rehabilitation,

So we've had a lot of presentations. They all tend to blur into each other but the presentation certainly didn't strike me as being anyway, you know, out of the ordinary. Just like you might have dietary problems maybe or you know other problems. This is just one of the things that can happen so it fitted in. (Centre1Patient13)

Patients, generally, considered the class content to be comprehensive, however, a few criticised the content for lacking detail and for being 'light' or 'basic'. Nevertheless the straight-forward approach and directness in dealing with sexual health was welcomed,

Whoever had presented it had just said, ok listen we're all grown up here, let's not try to use too many euphemisms, let's just get in here and call a dog a dog, you know kind of thing.

(Centre1Patient10)

Patients did not identify any of the topics covered as difficult or inappropriate and no patient reported being aware of any patient deciding not to attend the CHARMS class,

Nobody dropped out or nobody said they didn't want to take part in it or, you know, anything like that. (Centre1Patient13)

In contrast to the perception of some of the staff, most patients stated that they were not discomforted by the topic or the content of the class and that they did not detect discomfort or embarrassment from others,

I don't get embarrassed at that sort of thing. ... there was a girl in the class as well and I didn't think she was embarrassed either to be perfectly honest. But I wasn't, and I didn't notice anybody else squirming in their seat or anything like that. (Centre1Patient13)

Patients, generally, described the CHARMS class as relaxed and comfortable and reported that the presentation prompted discussion and questions,

we were all quite comfortable and there was discussion and questions (SJPT017)

A commonly reported response to the class content was laughter and it was suggested that humour was a predictable and natural response to a discussion about sex and that it served to alleviate embarrassment and thereby promote discussion,

There was a few times when ... we were like giggling teenagers ourselves. And it's a kind of, I think it's a natural reaction when you are talking about sex..... the ladies were coy and all the gents were giggling. But no, the information came across well. And there was a good discussion because of the fact that there was an element of humour attached, unintentional humour attached to it, it actually lightened the [atmosphere] (Centre1Patient10)

The skills of the staff delivering the class were identified as key to the positive response of the group

I thought the person who gave it was brilliant. Because she had a very personal touch, she is just a nice warm unembarrassed sort of person and witty as well. You know, she could actually be witty at times and all of that helped, you know, to keep us all unembarrassed and to keep us all interested. (Centre1Patient17)

Consistent with the opinion of the staff members, patients felt that positioning the class towards the end of the rehabilitation programme was very important as by this time staff and patients knew and were comfortable with each,

... but to me to have ten or fifteen strangers talking about, you know, problems with erections, problems with vaginal problems with, you know, all that type of thing – I don't think it would have went down well....basically they are all on first term names now, and you have a bit of a joke, and you do your thing, and I think it was much easier to lay it out then, and to ask the type of questions to people, once they were comfortable with one another. (Centre1Patient19)

A group setting rather than a one-to-one consultation was considered, by most patients, to be the optimal way of delivering the patient education class on sexuality. They spoke of the security which a group setting offers and the advantage of having queries answered and posed by others without having to ask the question themselves,

... in a group situation there they feel the comfort of the group or hiding in the group – they can be looking aloof but still engaging and getting the information ... and nobody is going to feel isolated or singled out (Centre2Patient5)

...what I found in the group session is that what you do is, you feed off other people, you know? ...– I mean there was a couple of questions I didn't have to ask because someone else asked them before me, so I got the answer even though I hadn't asked the question.

(Centre1Patient19)

However, the class was criticised by some participants as 'couple focussed' and therefore, not inclusive of people currently not in an intimate relationship,

... it seemed to assume that everybody had a partner. And I was sitting there, and I hadn't got a partner, you know, ... even just to say that, that perhaps one or two of you are not in a relationship, but that doesn't mean you won't be. Because, you know, I think just those few words would make a difference. (Centre1Patient17)

Patients from each centre also suggested that information given in the class should be supplemented by written details about how further advice or support could be accessed. Although patients in one centre reported receiving repeated assurances that a particular member of the team was available to offer individual advice or support,

Oh yes she was very, explicit on that, she gave them all the information, she told them if they didn't feel comfortable speaking, ... that there is people there that they can ring and they'll go one-to-one with them, ... (Centre1Patient19)

patients from the other centre did not report such assurances,

...I got the impression that a topic was brought up and it was dealt with but there was a feeling of a full stop at the end. You know, the information has been provided now.

(Centre2Patient5)

No patient recalled receiving a specific invitation for their partners to attend the CHARMS patient education class. However, as with staff, patients were concerned that the presence of a partner could be construed as an indication that a couple were experiencing sexual difficulties. Patients also feared it would cause embarrassment or would negatively change group dynamics,

I think partners would probably be a bit embarrassed in a group like that...somebody coming in that they wouldn't know the other people in the group and might feel a bit embarrassed

(Centre1Patient13)

Theme 3: Reflections

The key benefits identified by patients was a heightened awareness of the connection between sexual function and cardiovascular health and the knowledge that help was available if needed,

you are made aware of a problem that could happen, may not happen but could happen and if it does happen, you have somebody to go and talk to about it. (Centre1Patient13)

Patients experiencing sexual difficulty spoke of the reassurance of realising that such problems were not unique to them,

Believe it or not, it does take a weight off your shoulders because you know you are not the only one (Centre1Patient5)

Whether or not they were experiencing problems, most patients believed that a class on sexuality was an important and a natural inclusion in cardiac rehabilitation and some commented that cardiac rehabilitation would be incomplete without such a class,

Yeah, so I think it's a perfect situation to have it is in cardiac rehab... I think it's a necessary thing for people because you know there was a lot of talk about holistic health and holistic health sometimes overlooks sexual health. And the fact that CHARMS is dragging sex by the scruff of the neck into a general discussion of overall health, I think is brilliant. ... To my mind, if the CHARMS element of the cardiac rehab isn't there then it's not complete rehab because you're overlooking one very important element of people's health and that's sexual health. (Centre1Patient10)

Discussion

The value of qualitative research in trials is increasingly recognised [29]. Qualitative methods in pilot studies contribute important feedback not captured through other methods and help inform the further development of full trials [20]. The juxtaposition of the perspectives of staff, patients and partners in a single paper provides a unique insight into the experience of participating in a sexual counselling intervention from the perspective of those delivering and those receiving the intervention. The views of the staff and the patients deviated on a number of important points emphasising the value of the multi-perspectival approach. Overall, the findings demonstrate that the inclusion of the CHARMS staff-led patient education class was feasible and largely acceptable to the cardiac rehabilitation staff, patients and partners and gives support for the normalisation of sex education in cardiac rehabilitation. The two centres and the staff involved in this pilot study approached and delivered the intervention as intended but did so differently. These differences included the amount of information given to patients prior to the class, modifications made to the presentation and the number of healthcare professionals involved in the delivery of the patient education class. Some staff members compressed the number of slides in the presentation while still delivering all the information and this, and other modifications such as inserting a film clip, served to make the delivery more compatible with their personal

education style. The CHARMS intervention was pragmatically designed to have the potential to be implemented into general health services and to be feasible for health professionals to deliver [30]. Cardiac rehabilitation centres in Ireland vary in size and multi-disciplinary staffing mix [31-33] and cardiac rehabilitation programmes vary by centre [15]. The two centres involved in the CHARMS pilot study were diverse in their size and in the populations which they served and the differing approaches to the intervention was instructive. Context-level adaptations within trials do not necessarily constitute a threat to the integrity of an intervention [34] and through the development of clear parameters and reporting procedures, interventions can be designed to accommodate a degree of tailoring [17]. Indeed, complex interventions may work best if tailored to local circumstances rather than being completely standardised [17]. The modifications made by staff in this study will be reviewed and will usefully inform the development of the planned definitive trial of CHARMS.

Whereas previous studies have reported healthcare professionals reluctance or difficulty with providing sexual counselling [10, 35] staff were, on the whole, comfortable with delivering the content of the patient education class on sexual health. Nevertheless, some concerns persisted that a discussion on sexual matters might embarrass or make patients uncomfortable. Such concerns are similar to the findings in other studies [36-38]. However, these concerns do not reflect the experience of the patients who attended the class and the findings indicate that most patients perceived the inclusion of sexual counselling as a normal and unremarkable component of cardiac rehabilitation and as a natural component of a comprehensive cardiac rehabilitation programme. Although many staff reported that patients did not engage in much discussion or ask many questions during the class, patients were more inclined to report a relaxed and engaged class that prompted both questions and discussion. During the study a staff member commented that cardiac rehabilitation was a menu from which patients selected the information and advice of personal relevance to themselves and this seems to accurately reflect the attitude of most patients. Patients may benefit from information that is relevant to themselves and may be interested or even amused by information that is not of immediate relevance to them but the data in this study suggests that they are unlikely to be upset or offended.

These findings suggest that patients' sensitivities may be more robust than some healthcare professionals realise and healthcare professionals can address issues of sexuality with increased confidence that the information provided will not cause distress.

A group setting was considered by most patients to be a positive and safe context for the imparting of information about sex. Various benefits included the security of not being singled out for individualised information and the potential of having one's questions answered without having to ask. Positioning the class towards the end of the rehabilitation programme was identified by both staff and patients as a key strategy enhancing the acceptability of the class as participants had built up a rapport with each other and a positive group dynamic had been established.

The findings from this study add an interesting insight into the inclusion of partners in sexual counselling in cardiac rehabilitation. Partners of cardiac patients may be significantly impacted by sexual difficulties and international guidelines recommend the inclusion of partners in sexual counselling [2, 3, 13]. Cardiac patients and their partners have previously reported a preference for receiving information and support as a couple [39]. However, there was a consensus of opinion between staff, partners and patients in this study that the presence of partners could have a negative impact on the dynamic and comfort of the group. Importantly, it was also suggested that the attendance of a partner could be construed as an admission of a sexual problem and that people would be unlikely to expose themselves to the possibility of such an inference. Given the importance of the provision of sexual counselling for partners, it is clear that consideration must be given to how to adequately cater for their needs.

The concern raised by some patients that the class was 'couple focussed' is an important one for future development of the CHARMS intervention. Current sexual activity is not an indicator of potential future sexual activity [40] and it is therefore important to avoid alienating or distressing patients who are not currently in an intimate relationship. This study found that there was little unease or embarrassment reported by patients not currently sexually active or by those who did not expect to be sexually active in the future, reflecting the findings of previous research [41]. It is therefore

important to consider how adjustments could be made to the intervention to make it more explicitly inclusive of those not currently in a relationship.

All participating staff were committed to the ongoing provision of sexual counselling as part of their cardiac rehabilitation programme. The staff in one centre had previous training in sexual counselling and reported that they already provided much of the information contained in the CHARMS intervention, albeit in a less structured format. Cardiac rehabilitation staff from this centre were therefore less inclined to envisage implementing the CHARMS format in its entirety in the future. It may be that the CHARMS intervention may have more value to cardiac rehabilitation centres currently not offering sexual counselling as a routine component of cardiac rehabilitation.

Finally, all staff were to offer patients contact options to avail of follow up or more intensive help if required. However, a number of patients clearly were unaware of this as they highlighted the absence of an explicit follow-up pathway as a deficit of the CHARMS intervention. In future, therefore, the availability of follow-on support needs greater emphasis and patients should be provided with relevant contact details.

Conclusion

This study provides an in-depth insight into the experiences of patients and cardiac rehabilitation staff who participated in the CHARMS pilot study and their perceptions and opinions of the staff-led patient-education class on sexual activity. This qualitative study identifies that the class is an acceptable and feasible added component of cardiac rehabilitation. Overall, patients were very positive about the class, characterising it as both acceptable and necessary. Likewise cardiac rehabilitation staff were also largely positive although they would welcome more opportunity to tailor the patient education class presentation to their own teaching style and the particularities of the patients attending their programme. It is noteworthy, however, that the opinions and perceptions of the staff members and patients diverged on the response of the patients to the patient-education class on sexual activity and their level of comfort with it. However, the concerns of some staff that the

inclusion of the class would cause distress to the patients were not realised and the findings give support for the normalising of a discussion about sex in cardiac rehabilitation programmes. The findings of this study provide important data which will help shape and refine the CHARMS intervention in advance of a future definitive trial.

Limitations

The experiences and opinions in this study were those of rehabilitators in two cardiac rehabilitation centres and a small number of patients. These centres chose to participate in the CHARMS pilot study and may therefore have had a particular interest in, or openness to, patients' need for sexual counselling. The participants self-selected when agreeing to be interviewed and their opinions and experiences may not reflect those who did not agree to be interviewed. Nevertheless, the study provides important insights which will inform the further development of a definitive trial of the CHARMS intervention and may also have relevance to the development of other structured education sexuality classes in healthcare settings

References

1. Kriston L, Günzler C, Agyemang A, Bengel J, Berner MM: **Effect of sexual function on health related quality of life mediated by depressive symptoms in cardiac rehabilitation. Findings of the SPARK project in 493 patients.** *J Sex Med* 2010, **7**.
2. Steinke EE, Jaarsma T, Barnason SA, Byrne M, Doherty S, Dougherty CM, Fridlund B, Kautz DD, Mårtensson J, Mosack V *et al*: **Sexual counselling for individuals with cardiovascular disease and their partnersA Consensus Document From the American Heart Association and the ESC Council on Cardiovascular Nursing and Allied Professions (CCNAP).** *European Heart Journal* 2013, **34**(41):3217-3235.
3. O'Farrell P, Murray J, Hotz SB: **Psychologic distress among spouses of patients undergoing cardiac rehabilitation.** *Heart & Lung: The Journal of Acute and Critical Care* 2000, **29**(2):97-104.

4. Medina M, Walker C, Steinke EE, Wright DW, Mosack V, Farhoud MH: **Sexual Concerns and Sexual Counseling in Heart Failure.** *Progress in Cardiovascular Nursing* 2009, **24**(4):141-148.
5. Steinke EE, Jaarsma T, Barnason SA, Byrne M, Doherty S, Dougherty CM: **Sexual counseling for individuals with cardiovascular disease and their partners: a consensus document from the American Heart Association and the ESC Council on Cardiovascular Nursing and Allied Professions (CCNAP).** *Circulation* 2013, **128**.
6. Mosack V, Steinke EE: **Trends in Sexual Concerns After Myocardial Infarction.** *Journal of Cardiovascular Nursing* 2009, **24**(2):162-170.
7. Byrne M, Doherty S, Murphy A W, McGee H M, T. J: **The CHARMS Study: cardiac patients' experiences of sexual problems following cardiac rehabilitation.** *Eur J Cardiovasc Nurs* 2013, **12**.
8. Altıok M, Yılmaz M: **Opinions of Individuals Who have had Myocardial Infarction About Sex.** *Sexuality and Disability* 2011, **29**(3):263-273.
9. Brännström M, Kristofferzon M-L, Ivarsson B, Nilsson UG, Svedberg P, Thylén I: **Sexual Knowledge in Patients With a Myocardial Infarction and Their Partners.** *Journal of Cardiovascular Nursing* 2014, **29**(4):332-339.
10. Kolbe N, Kugler C, Schnepf W, Jaarsma T: **Sexual Counseling in Patients With Heart Failure: A Silent Phenomenon: Results From a Convergent Parallel Mixed Method Study.** *Journal of Cardiovascular Nursing* 2016, **31**(1):53-61.
11. Byrne M, Doherty S, Murphy AW, McGee HM, Jaarsma T: **The CHARMS Study: cardiac patients' experiences of sexual problems following cardiac rehabilitation.** *Eur J Cardiovasc Nurs* 2013, **12**.
12. Byrne M, Doherty S, McGee HM, Murphy AW: **General practitioner views about discussing sexual issues with patients with coronary heart disease: a national survey in Ireland.** *BMC Family Practice* 2010, **11**(1):40.

13. Doherty S, Byrne M, Murphy AW, McGee H: **Cardiac rehabilitation staff views about discussing sexual issues with coronary heart disease patients: a national survey in Ireland.** *Eur J Cardiovasc Nurs* 2011, **10**.
14. D'Eath M, Byrne M, Doherty S, McGee H, Murphy AW: **The Cardiac Health and Assessment of Relationship Management and Sexuality Study: A Qualitative Inquiry of Patient, General Practitioner, and Cardiac Rehabilitation Staff Views on Sexual Assessment and Counseling for Cardiac Patients.** *Journal of Cardiovascular Nursing* 2013, **28**(2):E1-E13.
15. Murphy PJ, Mc Sharry J, Casey D, Doherty S, Gillespie P, Murphy AW: **The CHARMS pilot study protocol: assessing the feasibility and acceptability of a sexual counselling intervention in hospital-based cardiac rehabilitation in Ireland.** *BMJ Open* 2016, **6**.
16. Mc Sharry J, Murphy PJ, Byrne M: **Implementing international sexual counselling guidelines in hospital cardiac rehabilitation: development of the CHARMS intervention using the Behaviour Change Wheel.** *Implementation Science* 2016, **11**(1):134.
17. Craig P, Dieppe P, MacIntyre S, Michie S, Nazareth I, Petticrew M: **Developing and evaluating complex interventions: the new Medical Research Council guidance.** *BMJ* 2008, **337**.
18. Rapport F, Storey M, Porter A, Snooks H, Jones K, Peconi J, Sánchez A, Siebert S, Thorne K, Clement C *et al*: **Qualitative research within trials: developing a standard operating procedure for a clinical trials unit.** *Trials* 2013, **14**(1):54.
19. O'Cathain A, Goode J, Drabble SJ, Thomas KJ, Rudolph A, Hewison J: **Getting added value from using qualitative research with randomized controlled trials: a qualitative interview study.** *Trials* 2014, **15**.
20. O'Cathain A, Hoddinott P, Lewin S, Thomas KJ, Young B, Adamson J, Jansen YJ, Mills N, Moore G, Donovan JL: **Maximising the impact of qualitative research in feasibility studies for randomised controlled trials: guidance for researchers.** *Pilot and Feasibility Studies* 2015, **1**(1):32.

21. Cooper C, O’Cathain A, Hind D, Adamson J, Lawton J, Baird W: **Conducting qualitative research within Clinical Trials Units: avoiding potential pitfalls.** *Contemp Clin Trials* 2014, **38**.
22. Bradley Fiona, Wiles Rose, Kinmonth Ann-Louise, Mant David, Madeline. G: **Development and evaluation of complex interventions in health service research: case study of the Southampton heart integrated care project (SHIP).** *BMJ* 1999, **318**(711).
23. Sandelowski M: **Whatever happened to qualitative description?** *Research in Nursing & Health* 2000, **23**(4):334-340.
24. Neergaard MA, Olesen F, Andersen RS, Sondergaard J: **Qualitative description – the poor cousin of health research?** *BMC Medical Research Methodology* 2009, **9**(1):52.
25. **NVivo.** In., 10 edn; 2012: NVivo qualitative data analysis software [program]
26. Hsieh H-F, Shannon SE: **Three Approaches to Qualitative Content Analysis.** *Qualitative Health Research* 2005, **15**(9):1277-1288.
27. C. Houghton, D. Casey, D. Shaw, Murphy. K: **Rigour in qualitative case-study research.** *Nurse Researcher* 2013, **20**(4):12-17.
28. YS Lincoln, Guba E: **Naturalistic Inquiry.** Newbury Park CA: Sage Publications; 1985.
29. Drabble SJ, O’Cathain A, Thomas KJ, Rudolph A, Hewison J: **Describing qualitative research undertaken with randomised controlled trials in grant proposals: a documentary analysis.** *BMC Med Res Methodol* 2014, **14**.
30. Byrne M, Doherty S, Fridlund BG, Martensson J, Steinke EE, Jaarsma T: **Sexual counselling for sexual problems in patients with cardiovascular disease.** *The Cochrane Library*; 2016.
31. Delaney M, Flynn R, Kiernan M, Doyle F, Lonergan M, Ingram S, McGee H: **Third National Survey of Cardiac Rehabilitation Service Provision in Ireland: progress on the 1999 National Cardiovascular Health Strategy Recommendations.** In: *Psychology Reports Paper 2.* Dublin; 2006.

32. Children DoH: **Changing Cardiovascular Health. National Cardiovascular Health Policy 2010-2019.** In. Dublin: Government Publications; 2010.
33. Department of Health and Children: **Changing Cardiovascular Health. National Cardiovascular Policy 2010-2019.** In. Dublin: Government Publications; 2010.
34. Hawe P, Shiell A, T. R: **Complex interventions: how "out of control" can a randomised controlled trial be?** *BMJ* 2004, **328**.
35. Vassiliadou A, Stamatopoulou E, Triantafyllou G, al. e: **The role of nurses in sexual counselling of patients after myocardial infarction.** . *Health Science Journal* 2008, **2**:111-118.
36. Barnason S, Steinke E, Mosack V, Wright DW: **Exploring Nurses' Perceptions of Providing Sexual Health Counseling for Patients With Cardiac Disease: Implications for Evidence-Based Interventions.** *Dimensions of Critical Care Nursing* 2013, **32**(4):191-198.
37. Hoekstra T, Lesman-Leegte I, Couperus MF, Sanderman R, T. J: **What keeps nurses from the sexual counseling of patients with heart failure?** *Heart & Lung: The Journal of Acute and Critical Care* 2012, **41**(5):492-499.
38. Jaarsma T, Strömberg A, Fridlund B, De Geest S, Mårtensson J, Moons P, Norekval TM, Smith K, Steinke E, DR. T: **Sexual Counselling of Cardiac Patients: Nurses' Perception of Practice, Responsibility and Confidence.** *European Journal of Cardiovascular Nursing* 2010, **9**(1):24-29.
39. Liljeroos M, Ågren S, Jaarsma T, Strömberg A: **Perceived caring needs in patient-partner dyads affected by heart failure: A qualitative study.** *Journal of Clinical Nursing* 2014, **23**(19-20):2928-2938.
40. Lindau ST, Schumm LP, Laumann EO, Levinson W, O'Muircheartaigh CA, Waite LJ: **A Study of Sexuality and Health among Older Adults in the United States.** *The New England journal of medicine* 2007, **357**(8):762-774.
41. Crumlish B: **Sexual counselling by cardiac nurses for patients following an MI.** *British Journal of Nursing* 2004, **13**(12):710-713.

