Reasons for dropout in the transition from hospital to municipality during exercise-based cardiac rehabilitation in a Danish cross-sectorial setting: a qualitative study

Anders Ravn holt Schüsler Damlund, Lars Bo Jørgensen, Birgitte Blume, Søren T Skou, Lars H Tang, Tom Møller

ABSTRACT

Objectives Despite documented benefits of cardiac rehabilitation (CR), attrition rates remain relatively high. Insights on patient perspectives concerning dropout during transition phases are deficient. This deeper understanding may help to inform on the perceived benefits and barriers in CR. This qualitative study explores the reasons why patients’ dropout during the transition from a hospital-based CR programme to local healthcare facilities.

Setting A Danish hospital and seven local healthcare centres.

Participants Twelve patients, who had dropped out of exercise-based cardiac rehabilitation (exCR) during the transition from hospital-based rehabilitation to local healthcare centres, were recruited to semistructured interviews based on a purposeful sampling.

Results Important patient needs during rehabilitation was the ability to identify and reflect oneself in a group of peers in a safe, specialised hospital-based environment. At the transition point, the meaningfulness of continuation of CR was revaluated. Findings showed that reasons for discontinuation varied within individuals. It encompassed on a balanced choice of reasessing benefits against competing agendas as work demands versus expectations of benefits in a changed exercise environment and own exercise capabilities.

Conclusion The study indicated that perceived meaningfulness may be a major motivational driver for both initiating and making a judiciously choice of leaving an exCR programme.

INTRODUCTION

Cardiovascular disease represents the leading cause of death in Europe. Patients newly diagnosed with a heart condition are recommended to attend cardiac rehabilitation (CR) to reach the best possible physical and mental state following their cardiovascular diagnosis and to return to activities of daily living. Based on international guidelines and national recommendations, the content of CR includes exercise-based modalities combined with multidisciplinary patient education and smoking cessation as central elements.

Systematic reviews on exercise-based CR (exCR) have shown that a higher volume of exCR has a significant effect on major health-related parameters such as mortality rate, recurrence of cardiovascular events and quality of life. Despite this, CR attendance rates in Europe remain a challenge and unfavourable social determinants (eg, lower educational level and income, living alone, rural residence, being a smoker) present a risk of compromising attendance rate. Likewise, adherence to exCR may be problematic, as indicated by a 2017 Danish study reporting that just 62% of patients adhered to more than 50% of the planned exCR sessions. Qualitative studies have shown logistics as a barrier to participation in single setting specialised exCR programmes. To reduce potential barriers, exCR programmes have generally moved to local healthcare centres.
centre settings, or as in the present study, a shared intervention with a transition between the hospital and the municipality setting. The aim of this joint setup is to facilitate and create easier access to greater locally based social support for patients.

Accordingly, patients newly diagnosed with a chronic heart disease are offered a 12-week exCR programme split between the patient’s hospital (hospital-based rehabilitation) and local healthcare centres (municipal-based rehabilitation), referred to as phase II-a and II-b, respectively. This approach sought to provide patients with a specialised exCR transition from hospital to municipalities, conveniently bringing exCR closer to the patient. How transition phases influence patient perceived pathways in split CR programmes are deficiently explored. Recent qualitative studies on discontinuation have examined dropout from specialised cardiac phase II rehabilitation without involving transitional phases.

As a result the Dropout during a 12-week exCR programme: A cohort study, called AoRTA, was established. Of the 279 individuals who participated in the 12-week exCR programme mentioned above, the AoRTA study identified 103 dropouts, 72 (70%) of whom stopped at the transition point. The fundamental question for this qualitative inquiry was to ask: Why are patients’ attending a hospital-based exCR programme and why are they leaving at the exCR municipality transition point?

**MATERIAL AND METHODS**

**Design**

Anchored in qualitative health research, this was an exploratory, interpretative qualitative study that drew on aspects of intuitivism and hermeneutic interpretation. In-depth, semistructured interviews (n=12 informants) were conducted and analysed using systematic text condensation based on Malterud. The consolidated criteria for reporting qualitative research checklist was used to guide manuscript development.

**Informants and procedure**

Recruited from the AoRTA study, informants had been diagnosed with a chronic heart disease, assigned to exCR by their cardiologist and received a preliminary consultation with a physiotherapist prior to starting exCR. The AoRTA exCR study included all types of heart diagnoses, for example, aorta stenosis, heart failure, stable and unstable angina pectoris and ST-elevated and non-ST-elevated myocardial infarction. The only exclusion criterion was that informants were required to be able to read and speak Danish fluently.

The AoRTA study recruited 279 patients, 103 (39%) of whom dropped out of the exCR programme. Out of the 103, there were 72 (70%) who dropped out during the transition from hospital-based to municipal-based exCR. The current study aimed to recruit a purposeful sampling of patients who dropped out during the transition phase, with the aim of achieving variation among the informants according to age, gender, marital status and diagnosis. Two additional informants were recruited following analysis of the initial 10 interviews, to enhance data saturation. The primary investigator (ARSD) contacted and recruited potential informants via telephone. After informed verbal consent was obtained, informants chose whether they wanted to do a face-to-face interview in their own home or at the hospital. In one case, the informant was permitted to do a telephone interview. The primary investigator reflected on his experience and possible preconceptions prior to doing the interviews in an effort to prevent them from affecting the interview situation as little as possible. Interviews, which where audio-recorded and subsequently transcribed verbatim, lasted 20–59 min (37 min on average). The primary investigator conducted all 12 interviews, reviewed the transcriptions and compared them to the audio file for accuracy.

**Interview guide and qualitative analysis**

An interview guide was developed based on a systematic review of qualitative research literature within exCR that included five studies focusing on physical, mental, work-related or personal factors, as well as system-related factors linked to rehabilitation dropout and adherence. To broaden the primary investigator’s preconceptions of CR, the two physiotherapists responsible for exCR were interviewed to incorporate their perspectives based on clinical experience with hospital-based exCR and patient safety aspects in the interview guide. The initial guide underwent minor changes after being tested in a pilot interview that was subsequently included in the final analysis (online supplemental file 1: Interview guide).

The interviews were analysed using systematic text condensation driven by an inductive and interpretative approach that involved compiling information from various informants. During the condensation phase, a variety of themes emerged, with the analyses aiming to identify similarities, differences and variations in the experiences and attitudes of informants. The primary investigator, a senior researcher (TM) and the authors discussed and developed the themes to obtain a wider analytic space and, finally, consensus based on interpretative recontextualisation. The research team comprised ARSD, LB (project manager for original AoRTA study), BB (all three specialised in cardiology), LIHT (associate professor and senior researcher with extensive CR expertise), STS (professor in exercise and health) and TM (associate professor and senior researcher with extensive qualitative research experience). ARSD had no previous contact with any of the informants.

For the sake of transparency in terms of the condensation phase, table 1 provides an audit trail sample.

**Patient and public involvement**

No patient involved. Results will be disseminated to patients through an oral presentation and hand-outs of the final article.
RESULTS
During the analysis meaningful segments were condensed and synthesised into 33 non-hierarchical categories and then condensed into eight emergent themes. Finally, these themes were incorporated into two overarching themes: (1) initiating exCR and (2) transition and discontinuation—a self-management option, which elaborate on and encompass the informants’ views and variations in terms of specific aspects of exCR. The findings indicate that the transition from hospital to municipal-based exCR may cause discontinuity in the perceived meaningfulness of the rehabilitation (online supplemental file 2: Coding tree). Table 2 provides the characteristics of informants.

### Theme 1: initiating exCR
A safe, relevant and supportive peer group environment
The informants stated that exCR was highly relevant after a cardiac event and agreed that the rehabilitation programme helped them resume usual physical activities or allowed them to test their physical abilities in a safe environment (table 3, Q1 and Q2).

**Q1:** Yes, I was nervous [about starting physical activity]; that’s why I felt great about starting at the hospital … That made me happy. (Informant 275, female, ages 60–70 years old)

The feeling of safety in doing strenuous physical activity was most important in order to push their boundaries without fearing a new cardiac event. This sense was related to the close monitoring by their physiotherapists and having doctors nearby. Several expressed confidences in the attending physiotherapists skills at the hospital (table 3, Q3).

**Q3:** There wasn’t a single moment where you were alone. There was a lot of emphasis on this. I could feel it, and I kind of liked that. It gave a feeling of safety. … For me, it’s all a question of my physical limitations and abilities. I felt that it was 100% the same at the hospital in the cardiac out-patient clinic and for the physiotherapists. (Informant 150, male, ages 40–50 years old)

They experienced that the physiotherapist could answer most questions that the patients had and received guidance about dietary supplements while feeling that the physiotherapist knew the individuals’ diagnosis and situation (table 3, Q4).

### Table 2 Characteristics of informants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Outcome</th>
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<tbody>
<tr>
<td>Sex (male, n / female, n)</td>
<td>8/4</td>
</tr>
<tr>
<td>Age (median; range)</td>
<td>71 (45–92)</td>
</tr>
<tr>
<td>Diagnosis (n)</td>
<td>Angina pectoris 3</td>
</tr>
<tr>
<td></td>
<td>ST-elevated myocardial infarction 4</td>
</tr>
<tr>
<td></td>
<td>Non-ST-elevated myocardial infarction 3</td>
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<td></td>
<td>Heart failure 3</td>
</tr>
<tr>
<td>Living alone (n)</td>
<td>4</td>
</tr>
<tr>
<td>Education</td>
<td>Primary or secondary school 4</td>
</tr>
<tr>
<td></td>
<td>Short-term (&lt;3 years) 4</td>
</tr>
<tr>
<td></td>
<td>Medium-term (3–4 years) 3</td>
</tr>
<tr>
<td></td>
<td>Long-term (≥5 years) 1</td>
</tr>
<tr>
<td>Work status (n)</td>
<td>Working 5</td>
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<tr>
<td></td>
<td>Retired 7</td>
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<tr>
<td>Income in DKK (n)</td>
<td>&lt;200,000 3</td>
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<tr>
<td></td>
<td>350–450,000 3</td>
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<td>450–600,000 2</td>
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<td></td>
<td>600–700,000 1</td>
</tr>
<tr>
<td></td>
<td>&gt;700,000 2</td>
</tr>
<tr>
<td></td>
<td>Missing data 1</td>
</tr>
<tr>
<td>Smoker (yes, n)</td>
<td>1</td>
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<tr>
<td>Other chronic diseases (n)</td>
<td>2</td>
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</table>
The informants emphasised that the flexible, individualised workouts allowed everyone to participate at their own level and that being paced during sessions was a positive aspect. Some thought that the variation was positive and provided the space to try new exercises, helping to provide inspiration when engaging in physical activity on their own. One informant felt that the hospital-based exCR was structured and that the staff were experienced in their field (table 3, Q5).

One informant specifically stated that he needed the class and would not have survived mentally without it (table 3, Q6). Another person reported that he might have been able to do the workouts on his own, but that it would have taken longer and not felt as safe, hence the setting provided the impetus to overcome any mental barriers in terms of taking the first step (table 3, Q7).

Q7: Yes, of course I would be able [to do without hospital exCR] ... It wouldn’t have been as good or as safe. In reality, I would have done worse without the hospital-based programme. It would have taken longer, and I would have struggled more with my motivation. (Informant 150, male, ages 40–50 years old)

Most informants did not experience disease progression or serious adverse events during hospitalisation. One informant suffered a cardiac arrest several times before initiating rehabilitation. Another informant was relieved about the exCR programme since he had unanswered questions after being released from the hospital that were answered during exCR. Notably, nearly all informants mentioned how satisfactory and comforting it was to be able to talk about one’s illness and symptoms, ask questions and receive peer support during sessions. Within the group and across age groups, patients were able to find support and nurture hope in each other by sharing and reflecting on their experiences with others in a similar situation. Several informants noted that the humour and sense of camaraderie that emerged were appealing, helping to motivate attendance. Several informants referred to their class and fellow patients as a positive experience (table 3, Q8–Q9).

Q9: It was nice to be able to talk about it with peers, because our different experiences have similar aspects. ... I believe that’s important. (Informant 268, male, ages 50–60 years old)

A few informants felt that they did not fit in as well due to their young age, while another felt it was because of continued heart disease symptoms. Just one felt that she would have managed fine without the hospital-based exCR since she had attended a local fitness class for a long time and would have continued to do so.

Theme 2: transition and discontinuation—a self-management option

All of the informants included in this study dropped out of the exCR programme during the transition from hospital-based to municipal-based exCR. At the transition
Table 4: Quotes (Q) by informants illustrating the overarching theme: transition and discontinuation—a self-management option

<table>
<thead>
<tr>
<th>Table 4 option</th>
<th>Quotes (Q) by informants illustrating the overarching theme: transition and discontinuation—a self-management option</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q10</td>
<td>‘You’re stronger after the six weeks and have gained insight into what you need to do. I think that was fine. Of course, there’s something available locally, but I don’t think it’s as specialised.’ (Informant 189, male, ages 50–60 years old)</td>
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<tr>
<td>Q11</td>
<td>‘I was ready and raring to go but I had a lot on my plate. That was the reason why I chose not to attend the local programme.’ (Informant 291, male, ages 50–60 years old)</td>
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<tr>
<td>Q12</td>
<td>‘I was supposed to transition to the local healthcare centre but that’s when things got sticky. I had a full-time job and had slowly started working while also doing the hospital exercise-based cardiac rehabilitation. At the end I was working full time, but the class being at one pm actually fit my schedule great.’ (Informant 172, male, ages 50–60 years old)</td>
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<tr>
<td>Q13</td>
<td>‘I thought it was fine with six weeks, because you got strong and had deep insight into how much you had to do. I feel like I’m good at listening to my own body and how much I can do. I believe that’s a great advantage.’ (Informant 189, male, ages 50–60 years old)</td>
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<tr>
<td>Q14</td>
<td>‘Now I’ve seen how much people can do and how much you can actually push yourself. I feel competent enough to administer my own training … I feel that this has really helped me dare to start training, and I want to start. I’m my own worst obstacle. I gained some tools and could ask questions about my heart and pulse. I think it would have taken me much longer to get started if I had not done that class.’ (Informant 275, female, ages 60–70 years old)</td>
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<td>Q15</td>
<td>‘I think that it [going to the gym] is fine. I do it with my daughter, but she uses the treadmill. … It’s more fun when 2–3 people go. … I think they’re keeping half an eye on me, but they don’t say so and that’s fine.’ (Informant 189, male, ages 50–60 years old)</td>
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<td>Q16</td>
<td>‘My wife bought an ergometer many years ago; we found it and set it up again. We have started using it, without any difficulties … I think we’re really good at supporting each other.’ (Informant 268, male, ages 50–60 years old)</td>
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Eleven out of the 12 informants chose self-administered workouts instead of municipal-based exCR, the majority of whom had prior experience with self-administered workouts and felt ready to continue working out alone. Some of these informants noted that, if their hospital-based exCR had lasted the full 12 weeks, they might have completed the entire programme. Accessibility and transportation issues related to rehabilitation services generally did not influence whether the informants had dropped out (table 4, Q10).

Q10: You’re stronger after the six weeks and have gained insight into what you need to do. I think that was fine. Of course, there’s something available locally, but I don’t think it’s as specialised. (Informant 189, male, ages 50–60 years old)

Consequently, what was otherwise intended as a convenient transition for the patients became an option of whether the exCR should be externally based or done independently. The informants’ re-evaluation of their own life agendas potentially influenced this decision (table 4, Q11–Q12).

Q12: I was supposed to transition to the local healthcare centre but that’s when things got sticky. I had a full-time job and had slowly started working while also doing the hospital exercise-based cardiac rehabilitation. At the end I was working full time, but the class being at one pm actually fit my schedule great. (Informant 172, male, ages 50–60 years old)

Although some informants still had concerns about their illness during the transition, none of them reported being limited by this in their daily living. Five informants mentioned an increased ability to manage and continue their new level of physical activity. Several informants mentioned an increased body consciousness and symptom management as the primary result of participating in hospital-based exCR (table 4, Q13–Q14).

Q14: Now I’ve seen how much people can do and how much you can actually push yourself. I feel competent enough to administer my own training … I feel that this has really helped me dare to start training, and I want to start. I’m my own worst obstacle. I gained some tools and could ask questions about my heart and pulse. I think it would have taken me much longer to get started if I had not done that class. (Informant 275, female, ages 60–70 years old)

Five out of 12 informants were actively working up until their cardiac event, and in no cases did their heart condition affect their ability to resume their usual jobs. A few had concerns about the risk of a new cardiac event due to a stressful job or as a result of doing high-resistance training. Almost all informants reported receiving support from their partner, family or friends in making changes to their daily living, like helping them make dietary changes, with smoking cessation or maintaining usual workouts. Some informants found that their partners or family continued to have concerns and were afraid that they might have another cardiac event while no one was around. Half of the informants specifically mentioned their partner’s support as an important part of their continued increased physical activity (table 4, Q15–Q16).

DISCUSSION

The present study contributes with a unique perspective on patient experiences in terms of dropping out of an exCR that switches from initially being hospital-based to subsequently taking place in a local healthcare centre (municipal-based). Overall, our findings indicate that the level of meaningfulness perceived among exCR patients may be crucial to...
both initiating rehabilitation and the patient’s re-evaluation of needs and abilities at the transition point, making the continuation of exCR a matter of being a personally weighed choice on the part of the patient. This is somewhat controversial as it goes against the expected benefits of maintaining a high level of exCR adherence.16–20 Based on the present study one could argue that attendance and making a judicious choice to leave an exCR programme are distinct but also equally meaningful positions.

In terms of initiating rehabilitation, the study is in accordance with previous findings showing that patients are more likely to attend if exCR programmes are group based, if sessions are planned and if the content is structured.14,15 Moreover, the informants said that the supervision received from exCR professionals provided valuable support, as did being part of a group in a structured training programme during the hospital-based sessions. The interaction with trainers in a safe environment, along with meaningful peer support, made it possible for patients to seek advice and compare experiences with patients in a similar position, as other research also indicates.16–17 Based on informant experience, a loss of peer support resulting from being referred to classes comprising patients with a variety of other diagnoses and within a changed setting at transition may affect the meaningful cohesion of the class, triggering them to consider discontinuation. The risk of not adhering to exCR programmes is found to be higher if communication is lacking and the programme aim becomes unclear.15–17 Moreover, Desveaux et al showed that less specialisation and a lack of individualisation gave patients participating in exCR more concerns in terms of continuing the programme.17

Existing qualitative research has identified multifactorial reasons for dropout from exCR. In general, the present qualitative study can neither confirm nor reject that factors, such as increased body mass index, comorbidities, sex and being >70 years of age, single, low income, less educated and an active smoker, increase the risk of dropping out.8,18,31 Accordingly, the present findings are more aligned with similar findings from a meta-synthesis of qualitative studies concluding that system-level barriers, for example, lack of individualised exCR and conflicting patient-level barriers (eg, commitments to work), are predictors for non-adherence or dropout.3 Our findings indicate that several informants who decided to attend municipal-based exCR had prior experience with self-administered workouts, just as various reasons for resuming self-administered workouts earlier than expected were given. They mentioned, for example obligations to one’s workplace or a wish to simply resume usual workout routines. Previous studies have found that patient obligations to their workplace were a large barrier to participating in exCR,14 15 30 which underscores the presence of competing agendas during rehabilitation stages and the heightened relevance of the transition phase. To accommodate patients’ daily living it is worth considering home-based CR for some, as a recent study has found it to be a safe alternative to regular exCR.32 Our findings do not contradict this perspective as a possibility for some patients based on their abilities and preferences.

Moreover, some informants expressed a negative attitude towards municipal-based exCR, which were affected by poor facilities at the rehabilitation centre or a prejudice towards municipal-based rehabilitation services. Based on informants’ experiences or attitudes, it may be relevant to investigate if current municipal training facilities are sufficient to handle exCR. On the other hand, most informants expressed an increased ability to manage and continue their newfound level of physical activity. Consequently, at termination of hospital-based exCR the referral to continued municipal-based exCR may have been perceived as a cross-road and as an option for reassessment of needs rather than a direct continuation of the programme. By declining continued exCR, the informants chose to change their continued rehabilitation, going from a shared intervention with support from peers and health professionals to a self-managed intervention, implying a shift in the supportive structure and context. The impact a shift in a transition context imposes has recently been suggested as an overarching feature concerning how patients define their roles and self-imagining following, for example, specialised rehabilitation from spinal cord injury.33 This involves reassessment of needs and regaining meaningfulness in accordance with previous or altered life roles.33 Transferred to the present study, this implies that in order to ease access to care, a split exCR programme may unintentionally decrease the perceived relevance as the contextually embedded agendas may change when transitioning from being a patient at hospital to be a citizen in the community.

The vast majority of informants were able to resume self-administered workouts or increased physical activity in their daily living despite exCR discontinuation. Notably, we have in the present study no exact insights on the sufficiency on self-performed exercise compared with the level and intensity offered in the full exCR programme. Among the various immediate positive outcomes of exCR are improved self-esteem and social functioning, just as exCR has proved to support long-term healthy behaviours and the return to work, in addition to reducing the risk of readmission and aiding in the normalisation of daily living.8,10

Based on a salutogenic approach to our findings, self-efficacy represents an important personal ability to heighten one’s sense of control and contact with one’s own body following the initial exCR. Bäck et al, who found that a sense of self-efficacy in patients with cardiovascular disease affects their attitude towards exCR, also asserted that patients with previous workout experience had a higher level of self-efficacy and found resuming unsupervised workouts easier.16 Similar to the present study, informants in Bäck et al’s study expressed a strong desire to return to daily living as fast as possible. Two studies showing a correlation between a low level of self-efficacy and an increased risk of dropping out of exCR,31 34 however, seem to contradict the findings in the present study but in reality underline the importance and non-linearity of self-efficacy in patients undergoing exCR.
Patients with low self-efficacy could potentially have more difficulties maintaining regular workouts after hospitalisation with a critical disease, while patients with high self-efficacy could potentially successfully transition to self-administered workouts before the scheduled end of exCR. Dropout among patients in the latter group should not be seen as a problem if the patients feel confident and safe in their self-administered workouts. Instead, to decrease the risk of dropping out of exCR early, extra care should be given to patients exhibiting low self-efficacy.

In terms of methodological considerations, this highly novel study comprises informants who exclusively dropped out during the transition from hospital-based to municipal-based exCR in a local healthcare centre, which sheds light on patient experiences in this crucial shift in rehabilitation context. The study is highly relevant with split rehabilitation programmes, but has potential relevance for patients’ assessments and choices in all transitional phases during rehabilitation, for example, during transition from rehabilitation to patients own home and continued daily living. Recruited using purposeful sampling, the 12 informants represented both sexes, multiple age groups and diverse social demographics. Even though the sex distribution of the informants reflects the underlying participation in exCR,\textsuperscript{7,12} the potential under-representation of woman is a possible reason for dropout not being fully saturated. The study reached a thematic content saturation with 12 informants, but based on established literature focusing on women’s experiences with exCR, this study may have overlooked themes of the role as a primary caregiver and nuances on social support.\textsuperscript{31,32} Previous studies have shown that women are at higher risk of dropping out of exCR.\textsuperscript{8,18,31} Moreover, there was only a slight amount of ethnic variation among patients in the main AoRTA study, which is why we were unable to explore the possible effect of ethnicity on dropout in an exCR programme conducted consecutively in two different contexts. Finally, the study did not include patients with heart valve surgery, which is why findings may not be transferrable to this specific subgroup.

The study aims to ensure credibility by thoroughly identifying any relevant issues based on a systematic review of the literature and key informant interviews with exCR physiotherapists to develop the semi-structured interview guide. To increase transparency and provide an overview of the steps involved in the interpretation, see the online supplemental file 2: Coding tree, which contains the inductively generated coding tree. The coding, thematicisation and interpretation were continuously revised until the primary investigator and senior researcher reached a consensus on the themes and hierarchical structure. In terms of confirmability, the analytical steps were discussed with the entire research team, which supports the triangulation of findings.

In conclusion, this qualitative study indicates that informants carry out a reconsideration of their needs when transitioning from hospital-based to municipal-based exCR at a local healthcare centre. Our findings show that the interplay of patient needs, timely relevance, a specialised safe environment and peer support are significant factors involved in exCR adherence. However, these factors may decline during the transition stage, potentially triggered by competing agendas such as work obligations and the individual’s reassessment of their ability to continue physical activity independently. We assume that perceived meaningfulness is a major motivational driver for initiating and potentially making a judicious choice to leave an exCR programme. In terms of the predominant cause of discontinuation, we are unable to fully determine whether it is the loss of meaningfulness in relation to termination of the hospital-based exCR, the informants’ preconceptions concerning their ability to resume usual workout routines, or a combination of the two.

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**Contributors** ARSD, LBJ, BB and TM designed the project. ARSD conducted and transcribed the interviews. ARSD and TM analysed and interpreted findings, with substantial contributions from LBJ, STS and LHT. ARSD and TM drafted the manuscript, with revisions by LBJ, BB, STS and LHT. Final approval of manuscript to be published, along with responses to reviewers, was made by ARSD, LBJ, BB, STS, LHT and TM. ARSD submitted the study and is acting as guarantor of the study.

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**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Ethics approval** Potential informants received written information about the study describing their rights and anonymity. Informants provided verbal and written consent to both participating in the interview and to collection of data from their medical records. The data were handled according to existing guidelines and approved by the Danish Data Protection Agency (REG-003-2018). This investigation conforms to the principles outlined in the Declaration of Helsinki.

**Provenance and peer review** Not commissioned; externally peer reviewed.
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