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"Kicked out into the real world": prostate cancer patients' experiences with transitioning from hospital-based supervised exercise to unsupervised exercise in the community

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Abstract

Purpose Regular exercise is recommended to mitigate the adverse effects of androgen deprivation therapy in men with prostate cancer. The purpose of this study was to explore the experience of transition to unsupervised, community-based exercise among men who had participated in a hospital-based supervised exercise programme in order to propose components that supported transition to unsupervised exercise.

Methods Participants were selected by means of purposive, criteria-based sampling. Men undergoing androgen deprivation therapy who had completed a 12-week hospital-based, supervised, group exercise intervention were invited to participate. The programme involved aerobic and resistance training using machines and included a structured transition to a community-based fitness centre. Data were collected by means of semi-structured focus group interviews and analysed using thematic analysis.

Results Five focus group interviews were conducted with a total of 29 men, of whom 25 reported to have continued to exercise at community-based facilities. Three thematic categories emerged: *Development and practice of new skills; Establishing social relationships;* and *Familiarising with bodily well-being*. These were combined into an overarching theme: *From learning to doing*. Components suggested to support transition were as follows: a structured transition involving supervised exercise sessions at a community-based facility; strategies to facilitate peer support; transferable tools including an individual exercise chart; and access to 'check-ups' by qualified exercise specialists.

Conclusions Hospital-based, supervised exercise provides a safe learning environment. Transferring to community-based exercise can be experienced as a confrontation with the real world and can be eased through securing a structured transition, having transferable tools, sustained peer support and monitoring.

Keywords Prostate cancer · Androgen deprivation therapy, · Exercise · Transition · Qualitative research · Focus group interviews

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Introduction

Prostate cancer is the most frequently diagnosed malignancy in men in the western countries. As in most western countries, the incidence of prostate cancer has increased in Denmark and approximately 4400 men are diagnosed with prostate cancer each year [1]. Androgen deprivation therapy (ADT) is a cornerstone in the treatment of metastatic non-curative prostate cancer and is also used in combination with radiotherapy of prostate with curative intent. ADT reduces testosterone production and is associated with negative alterations in body composition such as increased fat and decreased lean mass [2], increased fatigue [3] and reduced quality-of-life (QoL) [4, 5]. Exercise has demonstrated efficacy for improving physical function, cancer-specific fatigue and QoL in men with prostate cancer undergoing ADT [6–10]. Guidelines recommend training to be considered for prostate cancer patients receiving castration treatment to meet side effects [11, 12]. Currently, supervised group-based exercise combining resistance and aerobic training two times a week for at least 12 weeks has shown the strongest data for exercise as an adjunct therapy to ADT [13–15]. However, exercise intervention trials including post-intervention follow-up have shown high attrition rates [14, 16, 17], reflecting the difficulty of long-term exercise maintenance in people with cancer in general and a stronger emphasis on exercise adherence has been recommended [18]. One study evaluating an exercise intervention trial for men with prostate cancer found the men to be wary about continuing to exercise in community-based fitness centres after participation in the trial and the men experienced challenges in relation to motivation and awareness about their situation in the fitness centres [19]. So far very little attention has been given to the transition from a supervised to an unsupervised setting and more attention to supportive components when transitioning from supervised to unsupervised exercise is therefore warranted. Against this background, the aim of this study was to explore the experiences of transitioning to unsupervised exercise in the community among men with prostate cancer undergoing ADT who had participated in a standard-ofcare hospital-based exercise programme.

Methods

To gain insights into experiences of transitioning to unsupervised community-based exercise this study applied an explorative, qualitative design. The study was a part of a prospective observational study [20] approved by the Danish Data Protection Agency. The Ethical Committee has received information about the study (reference no. H-16017765). According to Danish law further approval was not required due to its qualitative design.

A supervised, hospital-based group exercise programme

At the largest urological clinic in Denmark, a 12-week supervised hospital-based exercise programme has been implemented as standard-of-care and is offered to all eligible prostate cancer patients undergoing ADT. It is free as the hospital is placed within a publicly funded health care system. The programme begins with an educational session including information on prostate cancer, ADT and how exercise can mitigate treatment-related side effects. Each patient receives an individualised, progressive resistance training programme following the guidelines for progression recommended by the American College of Sports Medicine [21]. The resistance training is performed using exercise machines. Aerobic exercise supplements the resistance training. The training is carried out at the hospital twice a week in groups of 10–15 men and under the supervision of a physiotherapist. The last 2 sessions are performed in a community-based fitness centre. The programme monitors the effect on physical fitness with tests at start-up, after 12 and 24 weeks. The programme is described in detail elsewhere [20].

Sampling

A purposeful criteria-based sampling strategy was employed to obtain information-rich cases [22]. Eligible participants included men with prostate cancer undergoing ADT who had completed the supervised, hospital-based exercise programme at least 2–3 months prior and subsequently had experienced the transition to unsupervised, community-based exercise. Eligible men were contacted individually by telephone by the physiotherapist who supervised their hospital-based exercise to introduce them to the study. Informed consent was obtained from all included participants.

Data collection

Data were collected by means of focus group interviews. Interviews were conducted in groups of up to seven men who had participated in the same group during the programme at the hospital. A semi-structured, open-ended interview guide facilitated the interviews (Table 1). Interviews were conducted in a conference room at Herlev Hospital. Each interview lasted between 60 and 90 min and was audio and video recorded. The interviews were carried out by the first author MLKS and observed by JM and a candidate student, respectively. Prior to each interview, it was stressed that neither MLKS nor observers were health care personnel or members of staff responsible for the programme.

Analysis

Tape recordings were transcribed by MLKS using Microsoft Word. Transcriptions were checked against tape and video recordings for accuracy and analysed by means of thematic analysis [23]. The analysis was carried out by MLKS in close cooperation with two co-authors and experienced qualitative researchers (JM and PC). The analytic process was inductive and data were analysed by identifying themes on a semantic level moving from description by finding patterns to interpretation by signifying patterns and their broader meaning. First, initial notetaking with descriptive and linguistic comments was completed to produce a comprehensive set of codes grounded in the data from each interview. The codes were then sorted into potential themes. Following this, text segments were remarked in relation to the potential themes and mapped in relation to the domains: transition, exercise and the group. Potential themes were discussed between MLKS and JM to

 Table 1
 Focus group interview guide

Domain	Sample questions	Follow-up sample questions
Transition	What do you think worked well in the transition from supervised to non-supervised exercise? What challenged you in the transition from supervised to non-supervised exercise?	Why do you think X worked well? Why do you think X was particularly challenging? How could this challenge be met?
Exercise	What happens during an exercise session when you exercise in the fitness centre?How do you feel that your physique is influenced by exercise?	What did you bring along from the supervised exercise? When is it difficult to exercise without supervision? What do you do then?Do you experience that your physique has improved during the time you have exercised? How? How does this affect your daily life? How does it influence your inclination to continue exercising?
The group	What does it mean to you to exercise with each other? Are any of you exercising alone?	How do you support each other when exercising? How do you think it differs from exercising together with the others?

identify themes relevant for further analysis. The identified themes were reviewed by re-reading and re-marking transcripts. All new and earlier marked text segments across the transcriptions were compiled into one single document under the relevant theme to gain an overview of the themes across transcriptions. This involved a further abstraction by sorting the themes into three thematic categories with sub-themes followed by an identification of one overarching theme.

Descriptive analysis of continued exercise

Self-reported information on physical activity behaviour were supported by data from objective measurements of the participants' functional capacity and fitness assessed by means of 30 s Chair-Stand Test and Graded Cycling Test with Talk Test, respectively. These tests are described in details elsewhere [20]. Data were analysed using a mixed-effect model with unstructured covariance matrix and R version 3.3.3. Results are included in this report for descriptive purpose only.

Results

Twenty-nine men (Table 2) participated in five focus group interviews (Fig. 1). Twenty-five men reported that they were continued to exercise and overall a clinically and statistically improvement in physical fitness was observed after ended exercise programme with improvements maintained at 3 months post-programme (Table 3). Three thematic categories with eight sub-themes emerged and were combined into an overarching theme summarising the men's experiences of the transition from supervised to unsupervised exercise: *From learning to doing* (Fig. 2). Descriptive quotes are used as illustrative examples of the thematic categories and shown with participant number (e.g. P1) and marked with interview number (e.g. FGI 1).

Development and practice of new skills

The men experienced the supervised setting at the hospital as an organised and disciplined learning environment. Aerobic and resistance training using machines was a new way of doing exercise for most of the men and they considered the practical and technical use of the machines important to learn as it enabled them to operate the machines and feel in control when exercising.

P23: I have tried [before being diagnosed with prostate cancer] to join our local fitness centre but I didn't know the machines there, but now I know how to use a bike

Table 2Baseline participant characteristics (n = 29)

Age, years median (IQR)	71 (67–74)
ADT treatment indication	
Locally advanced PCa, no. (%)	5 (17)
Metastatic PCa, no. (%)	21 (72)
Adjuvant treatment w. EBRT, no. (%)	3 (10)
mCRPC, no. (%)	8 (28)
Duration of ADT, months median (IQR)	3.0 (2.0–14.0)
Short-term ADT (≤6 months), no. (%)	18 (62)
Long-term ADT (> 6 months), no. (%)	11 (38)
Known CVD, no. (%)	9 (31)
Known diabetes mellitus, no. (%)	5 (17)

ADT, androgen deprivation therapy; *CVD* cardiovascular disease; *EBRT* external beam radiation therapy; *IQR*, interquartile range; *mCRPC*, metastatic castration resistant prostate cancer; *PCa*, prostate cancer



*An exercise group represents men who had joined the same group in the 12-week hospital-based exercise programme.

with interval. This is something I didn't know anything about earlier. So that meant something as well, that we learned it (FGI 4)

The men experienced the structured transition (i.e. the last training sessions of the supervised programme were conducted in a community-based fitness centre) as important. It established a link to the community-based fitness centre and the practical introduction to the relevant machines in the fitness centre delivered by a physiotherapist from the hospital-based programme provided confidence in exercising independently. However, the men expressed individual variability regarding the amount of instruction they considered relevant when introduced to the machines and the community-based facilities. For some a simple introduction was enough, others reflected on how they would have preferred the presence of the physiotherapist, who pulled back during these sessions, resembling what they were used to in the hospital-based training.

P10: the first time we were out there, I wanted to have our instructor from here with us, so that it was them, who were on the machines out there, that could explain to us "there is a machine" and so on, it was very short P7: they came along, but it is right, they left very quickly P8: yes, and they had no uniform on P9: that I don't think is a problem, I think they showed us which machines it should be (FGI 2)

Table 3 Descriptive analysis of continued exercise of men (n = 29) participating in focus group interviews

Self-reported post-programme exercise behaviour at time of	f interview				
Median time since ended hospital-based exercise programme (weeks)					
Currently exercising (<i>n</i>)					
Not exercising (<i>n</i>)					
Context of exercise					
Exercising with men from the group (n)					
Exercising alone (<i>n</i>)					
Exercising with wife (n)					
Continued in a local fitness centre (<i>n</i>)					
Continued in a fitness centre under the management of a local association of pensioners (n)					
Pre- to post-test changes in physiological measurements					
	Baseline, mean (SD)	Change from baseline to 12 weeks (95% CI)	Change from baseline to 24 weeks (95% CI)	Total p value*	
Functional capacity assessed by means of 30 s Chair-Stand Test (number of times the patient stands)	15.6 (4.0)	3.2 (2.3–4.2)	4.8 (3.4–6.2)	<.0001	
Fitness assessed by means of a Graded Cycling Test combined with the Talk Test (watt)	108.1 (29.0)	27.4 (21.0–33.8)	27.3 (19.4–35.2)	<.0001	

The supervised, hospital-based exercise intervention monitors the effect on physical fitness to evaluate benefits of the intervention. The men were tested (Chair-Stand Test (CST) and Graded Cycling Test combined with the Talk Test (GCT-TT)) at baseline, post-intervention (12 weeks) and at 3 months follow-up (24 weeks). Within-person changes of 2.6 repetitions and 13 W for CST and GCT-TT, respectively are considered clinically significant [20].*Analysis used mixed-effect models, unstructured covariance matrix and R version 3.3.3

The men described how their individual exercise chart from the supervised period showing the machines and describing the different exercises became a tool when exercising on their own that enabled them to successfully complete their different exercises independently. Most of the men brought along the physical chart, while others had memorised it.

P2: we had a level for each machine put down and that means I know exactly...I have a rhythm and I know exactly how it should be done and how much weight there must be on (FGI 1)

Moreover, they explained how they progressed by adjusting the weight on a machine or adding new machines to their programme. The men felt able to continue making progress, but most identified the follow-up tests conducted at the hospital as important, with the physiotherapist recognising their training efforts.

P14: you want to show her [the physiotherapist] that you can maintain you physical fitness (FGI 3)

Establishing social relationships

The men highlighted the social relations between them as the most important factor in the transition to out-ofhospital training. They described how they together faced what was experienced as "a meeting with the real world". Two groups in particular successfully sustained their social relationships throughout and beyond the transition by formalising the group structure from the hospital training. One group made an agreement to continue exercising together and another group appointed a 'foreman'.

Interviewer: what have worked well in the transition? P3: being together has been good I think P5: it's important to have social closeness like we have, partly an active foreman, it's important that you appoint a foreman in the group (FGI 1)

Those men who reported that they continued exercising together after the transition to the community (n = 12), described how the social relationships extended beyond the whole group to smaller groups or pairs who met in different local fitness centres. They repeatedly emphasised the significance of *having a talk* with peers after a training session, which they considered as important as exercising itself. Sharing the same life event was experienced as an unspoken understanding of what it meant to have prostate cancer and in contrast, the men who were exercising alone or with their wives (n = 13)after the programme, stressed how they missed exercising and talking with peers. The majority of them



described how they unsuccessfully tried out strategies to find exercise partners similar to themselves.

P18: it would be lovely if one had someone to do the exercise with, do you exercise alone [on participant to another] P17: yes, but I would like to try to see if I can find someone at the same level as me...not the young ones, I go in the morning and I hope I can find someone, I'll continue to look...and then one might say "don't we often see each other here?" (FGI 3)

They found the environment in the fitness centres alienating when exercising alone among younger and more muscular men. Comparison with peers in a similar situation was no longer possible and this affected these men's attitudes toward exercise and challenged continuation of their exercise regimes.

P20: it's difficult to establish something together [in a local fitness centre], when one has different physical levels, but also different age, we don't have so much in common, so therefore we don't have so much in common when it comes to training, I'll give it a year and then I probably go back to my old routine with running, biking and swimming (FGI 4)

While those men who continued exercising together also commented on younger and more muscular men at the community-based facilities, this did not affect their attitudes toward exercise as it was possible for them to make relevant comparisons with other men with prostate cancer experiencing similar physical limitations imposed by prostate cancer and their treatment. The men identified living in different towns as the most important barrier for continuing to exercise together.

Familiarising with bodily well-being

The men described how the role of exercise in mitigating side effects of their treatment had motivated them to join the supervised programme at the hospital and this motivator was unchanged when transitioning to out-of-hospital training. Furthermore, the men explained how they came to experience improved physical strength that made it possible for them to engage more richly in daily activities and how doing exercise provided them with a sense of feeling better in their body, manifested as increased energy and more enjoyment.

P24: I think I get high of doing exercise, I can come home after an hour an half in the [fitness centre] and then my wife says "I'm going to the mall", I say "I'm coming with you", she says "we can take the car", I say "no, let's walk" and then she is a bit surprised, I think it's really good, also the day after, I think I feel better (FGI 5) Experiencing improved bodily well-being became a motivational factor for the men to continue exercising. However, despite these positive experiences the men also described how having a bad day or fatigue challenged going to the fitness centre.

P10: when I got up Tuesday morning I was feeling tired and if I didn't have the group then I would have found an excuse for not going to the fitness centre (FGI 2)

Discussion

In line with previous research [24], this study indicates that hospital-based group exercise intervention performed under the supervision of a trained physiotherapist provides a safe learning environment. This implies that transferring to community-based exercise may, as it was shown in the current study, can be experienced as a confrontation with the real world. However, a structured transition incorporating supervised training sessions in a community-based fitness centre allowed the men to familiarise with new facilities in a manner perceived as safe and controlled. Furthermore, attending a fitness centre as a group eased the transition further. Peer support engendered from participation in group-based interventions has been identified as important to facilitating intervention adherence [19, 24-26], and it has also been suggested to help keep participants committed to sustaining exercise behaviour after an intervention [24]. Findings of the current study support this, as peer support was identified as a key component aiding continued exercise. Specifically, the supportive camaraderie provided by attending a communitybased fitness centre with peers with whom the men could identify, was perceived positively and important in the 205

unsupervised setting. Sustainability of the peer group in the new setting was possible, but also difficult and required individual initiatives. While the majority of the men perceived exercising together as essential, only 48% successfully continued to exercise together in pairs or smaller groups, most likely due to logistical issues because geographical distance was identified as a barrier to continue exercising together. These smaller constellations are vulnerable constructions and may easily be dissolved. Overall, the above findings highlight the potential effect of peer-to-peer support in maintaining exercise motivation and self-efficacy across contexts and over time, but equally highlight the need for more attention on how to facilitate long-term peer-support. Research on breast-cancer survivors shows promising effects of peer-to-peer counselling in the adoption of exercise behaviour [27]. To date, peer-topeer support within the prostate cancer area has only been evaluated as a means to improve quality-of-life after radical prostatectomy [28, 29], and the potential benefits of a peer-led exercise intervention are yet to be elucidated.

Physical objects appear to play a central role in the men's continued exercise when transferring to an unsupervised setting. The emphasis on the importance of confidently using the machines in both settings reflects how the machines mediate the men's skills and experiences of being capable users of aerobic and resistance training, while their exercise chart supporting their individualised exercise prescription became a self-instructive tool. From a socio-material theoretical perspective, physical objects are understood as a constituent part of human experience and practice [30, 31] and might explain why the machines and exercise charts play a central role. Furthermore, the ability to confidently use the machines and ascribe instruction to oneself appeals to a more hands-on and action-orientated self-reliance that are found to facilitate men to get engaged in exercise [24, 32-34]. In this study moving from a position of learning to become a capable and self-reliant user of aerobic and resistance training kept the men engaged

 Table 4
 Suggested components

 to incorporate into the design of a supervised exercise intervention

 to support continued exercise

 participation in transitioning to

 unsupervised exercise

Challenges	Suggested components		
Aiding the transition from supervised to unsupervised exercise	A transition component that facilitates an introduction to community-based facilities (e.g. supervised exercise sessions delivered in a community-based fitness centre)		
Formalising group structure in the unsupervised setting to ensure higher occurrence of group sustainability post-programme and long-term peer support	Incorporation of strategies facilitating group sustainability across contexts (e.g. appointment of foreman or exercise buddies programme)		
Transferring knowledge from a supervised setting to unsupervised, community-based exercise to ensure that participants are cable and self-reliant users of aerobic and resistance training	Incorporation of transferable tools linked with values of self-reliance (e.g. personal exercise chart)		
Monitoring exercise progression when unsupervised	Access to medical and qualified exercise supervision for regular 'check-ups' (e.g. physiological assessments conducted at the hospital).		

and facilitated continued exercise in the transition to unsupervised exercise. It ensured that men experienced a continuous well-being (physical strength and feeling better), which they identified as an ongoing motivation for continuing to exercise. This process of becoming a capable and self-reliant user may be explained within a social learning theoretical perspective. Within this perspective, learning is a social act and embedded in our experience of participating in daily practices within the context of a specific group and is a resource in our identityforming process [35]. Hence, doing exercise can be understood as participation in a certain practice in which physical problems are alleviated and bodily well-being (physical strength and feeling better) is regained through identity-forming experiences as participation and engagement in exercise shapes the men's experience of themselves (e.g. to be self-reliant and stronger). Understanding motivation and continued exercise in the transition to unsupervised exercise within a sociomaterial and social learning perspective may add new dimensions to the most widely used theoretical behavioural change models in exercise-oncology, all of which are mainly based on rational reasoning (e.g. theory of planned behaviour) [36–39]. While this study confirms principles of self-efficacy, it equally underlines how adoption of sustainable exercise behaviour may be a matter of personal identification through participation in exercise in which physical objects such as machines and tools are a constituent part of practices and experiences. Additional research is required to explore this further.

The men highlighted the importance of physiological assessment, conducted by the physiotherapist after completion of the programme. The assessments served as an opportunity for the physiotherapist to provide quantitative feedback on the men's progress, allowing them to evaluate their own effort of being a capable user of aerobic and resistance training. This suggests that external accountability such as a formal linkage to health care professionals may not only facilitate initial exercise participation [40], but also provide a resource in continued exercise in the transition. Based on the findings from this study, we suggest that incorporation of specific components into the design of a supervised exercise intervention may ease the transition to unsupervised exercise and support continued exercise (Table 4). Further research is needed to evaluate the effectiveness of these components in adoption of long-term exercise in men with prostate cancer.

Methodological considerations

To the authors' knowledge, this is the first study examining how prostate cancer patients who had participated in a supervised, hospital-based programme experienced the transition to unsupervised, community-based exercise. By applying an explorative design, rich information was obtained allowing for the identification of a broad, but selected, range of themes. Due to this approach a relatively large sample size was established to gain sufficient information power [41]. From the dense specificity of experiences among the participants, the information power of this study is proposed to be high. However, the sample represents men who have accepted to participate in a programme which might suggest the men have been especially motivated to exercise. This may explain why men who failed to adhere to exercise beyond the transition were poorly represented (n = 4), leaving insufficient information power in relation to why some do not continue exercise. Also, evaluation of the effect of supervised, hospital-based intervention in relation to adoption of exercise behaviour long-term requires a randomised design and use of prospective and objective measurements. Engagement from the participants during the interviews was high. Video recordings and observational data have supplemented the audio recordings to incorporate the men's interactions during the interviews [42]. To enhance credibility, researchers with different scientific experiences collaborated in collecting and analysing the data [22]. To ensure transferability, detailed information regarding the context in which the work has been undertaken, and description of the phenomenon under exploration, has been provided [22, 43].

Conclusion

Hospital-based, supervised exercise provides a safe learning environment and transferring to community-based exercise can be experienced as a confrontation with the real world and this confrontation can be eased through securing a structured transition, having transferable tools, sustained peer support and continued monitoring.

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Compliance with ethical standards

Informed consent was obtained from all included participants.

Conflict of interest The first author, Mette L.K. Schmidt, has no conflict of interest to report. Mette L.K. Schmidt has the full control of all primary data and agrees to allow Supportive Care in Cancer to review the data if requested.

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