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## I exercise to postpone death – Interviews with persons with hip and/or knee osteoarthritis who are attending an osteoarthritis school

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### ABSTRACT

**Background:** Physical activity (PA) and exercise constitute the first line of treatment for osteoarthritis (OA) of the hip and/or knee. Even though the symptoms may vary, OA should be considered a chronic disease and therefore PA and exercise should be performed lifelong. That needs knowledge and motivation.

**Purpose:** The purpose of this study was to explore and create a deeper understanding of the motivational processes for PA and exercise for persons with hip and/or knee OA who have participated in a self-management program OA school that included long-term exercise supervised by physical therapists.

**Methods:** Twenty-two in-depth interviews were conducted with 18 participants recruited from the OA school at a Physical Therapy Rehabilitation Clinic in Sweden. The interviews were analyzed with qualitative content analysis.

**Results:** The analysis resulted in one main theme, Developing health literacy to encourage motivational processes for PA and exercise in OA and four themes: 1) meeting an established self-management program; 2) carrying my life history; 3) understanding the intelligence of the body; and 4) growing in existential motivation

**Conclusion:** Motivation for being physically active and to exercise, the life history in relation to PA and what creates existential motivation are important areas to ask questions about when people come to OA schools. Knowledge about the signals of the body connected to OA should be implemented in OA schools in order to motivate people to live an active life despite OA. Health literacy and the awareness of how PA can postpone death are likely to be important for existential motivation.

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Osteoarthritis; hip; knee; physical activity; exercise; physical therapy; motivation; health literacy

## Introduction

Osteoarthritis (OA) is common worldwide (Johnson and Hunter, 2014), and hip and/or knee OA is the leading cause of activity limitations (Brooks, 2002), defined by the World Health Organization (WHO) as the difficulties an individual may have in executing activities (World Health Organization, 2001). OA in the hip and/or knee can be experienced as pain, stiffness, or other symptoms that can lead to activity limitations, including difficulties in performing physical activity (PA) such as walking (King, Kendzerska, Waugh, and Hawker, 2018). Even if the experience of pain in OA can vary both in magnitude and duration the pain should be considered as chronic (Gatchel et al., 2007). It is also well known that pain during activities can be interpreted as a warning signal and lead to fear-avoidance behaviors. The validity of the avoidance model, i.e. the association

between pain during activity, psychological distress, avoidance of activities, muscle weakness, and activity limitation have been reviewed (Holla et al., 2014). All OA symptoms can also affect the sense of self and well-being, particularly because they influence people's ability to take on certain roles and participate in valued relationships (Ballantyne, Gignac, and Hawker, 2007). The European League Against Rheumatism (EULAR) recommends that health professionals adopt a patient-centered framework anchored in a biopsychosocial perspective (Geenen et al., 2018).

A combination of aerobic, strengthening, and endurance circuit exercises for people with hip and/or knee OA have, in a systematic review (Fernandopulle, Perry, Manlapaz, and Jayakaran, 2017), been found to be mostly positive on pain and physical function.

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Substantial gaps still remain in the quality of nonsurgical OA management (Allen et al., 2016). The WHO recommends, for adults, at least 150 minutes of moderate-intensity aerobic PA, or at least 75 minutes of vigorous-intensity aerobic PA, throughout the week in bouts of at least 10 minutes, together with muscle-strengthening activities (World Health Organization, 2010). Any amount and length (bouts) of exercise are having a beneficial impact on overall health (Singh, Patisapu, and Emery, 2020). Those in the lowest-activity groups, across levels of general and abdominal adiposity, can have the greatest reduction in mortality risk (Ekelund et al., 2015).

A generally active daily life, regardless of regular exercise, have been found to be associated with longevity in older adults (Ekblom-Bak et al., 2014). Physical inactivity is the fourth leading cause of death (World Health Organization, 2010). PA and exercise are essential health-promoting and disease-preventing non-pharmacological treatments of hip and knee OA (Fernandes et al., 2013; Zhang et al., 2010). People with hip and/or knee OA often have very low cardiorespiratory fitness (Philbin, Groff, Ries, and Miller, 1995) and incremental risk for developing: cardiovascular disease (CVD) (Hall et al., 2016); serious cardiovascular events (Hawker et al., 2014); stroke (Hsu, Lin, Li, and Chung, 2017); depression (Veronese et al., 2017); diabetes (Kendzierska et al., 2018); dementia (Huang et al., 2015); and premature death (Hawker et al., 2014; Nuesch et al., 2011). To avoid comorbidity and premature death, and to promote health, people with hip and/or knee OA should maintain physically active and exercise lifelong (Pisters et al., 2010).

Maintenance of PA and exercise can be influenced by a complex array of both extrinsic (external) and intrinsic (personal) factors (Dobson et al., 2016). Facilitators of PA in OA can be summarized in biopsychosocial aspects, such as positive exercise experiences and beliefs, knowledge, relief of symptoms, mobility, a “keep going” attitude, adjusting and prioritizing PA, social support, and access to professional health care support (Ryan and Deci, 2000). It has been shown that important barriers to exercise for people with OA are uncertainty about benefits of exercise, lack of OA knowledge, negative social and professional support, physical limitations, and pain (Kanavaki et al., 2017). Moreover, lack of self-efficacy about one’s capability also correlates to barriers of PA in OA (Dobson et al., 2016). Self-efficacy represents the level of personal agency and mastery of a specific behavior, likely related to task-efficacy (Bandura, 1997). The self-efficacy element has been shown to correlate with adherence to physical therapy as well as PA, and to

predict long-term effects of a combination of education and exercise (Rhodes and Fiala, 2009; Skou, Simonsen, Odgaard, and Roos, 2014).

Motivation is the critical variable in producing maintained change. According to Ryan and Deci (2000), the goal-orientated self-determination theory of motivation can be illustrated in a continuum from non-self-determined to self-determined motivation. There are various aspects of competence, relatedness and autonomy interfering in these self-determination motivational processes, and a lack of those needs are associated with poorer motivation. Furthermore, the capability to derive pathways to desired goals are also associated with self-esteem, self-efficacy, and optimism, all illustrated as hope-related aspects in hope theory (Snyder, 2002). The capability in pathways thinking means, how we link the present challenges to future goals. High-hope people manage to channel the requested motivation to the best available pathway. This capability in pathways thinking can be linked to the concept of health literacy (HL) defining how information is interacting within a person’s motivational processes, eventually leading to decision-making and behavioral changes. Living a good life with OA requires the ability to develop HL. According to Sorensen et al. (2012), HL can be defined as “*people’s knowledge, motivation, and competences to assess, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course*”. The motivational aspects of HL need to be understood in some depth in relation to OA and PA. People with OA needs a lot of information and knowledge to prevent unnecessary and dysfunctional misconceptions, underuse of potentially helpful treatment options, and uninformed decisions (Brembo et al., 2016).

Knowledge about motivation is important for the successful support of persons with OA to develop HL and enhance PA and exercise. There is a challenge to implement all this knowledge and transform it into self-management programs (Michie, van Stralen, and West, 2011), but it is not impossible. To enhance self-management and coping strategies, a supported OA self-management program, including education and the option of supervised exercise delivered by trained physical therapists called the OA school has in accordance with European guidelines (Fernandes et al., 2013), been developed in Sweden (Klæssbo, Larsson, and Harms-Ringdahl, 2003; Thorstensson, Garellick, Rystedt, and Dahlberg, 2015). The OA school has recently, in two articles, been found to decrease pain, increase the quality of life and increase self-efficacy, but not to increase the

level of PA or decrease the average amount of sedentary time (Jonsson et al., 2019, 2018). Strategies to maximize long-term adherence to exercise must be implemented (Bennell, Dobson, and Hinman, 2014), but there is a lack of in-depth knowledge about patients' experiences of motivational processes for PA and exercise when it comes to people with hip and/or knee OA attending OA schools. The aim of this study was to explore and understand more deeply the motivational processes for physical activity and exercise for persons with hip and/or knee OA who have participated in a self-management program OA school that included long-term exercise supervised by physical therapists.

## Methods

In this study, an explorative qualitative design, guided by content analysis (Graneheim, Lindgren, and Lundman, 2017), was used. Three main researchers (MK,<sup>1</sup> KN,<sup>2</sup> HW<sup>3</sup>) have conducted the design, data collection, and the analysis. Twenty-two in-depth interviews with 18 participants were conducted with participants recruited from the supported OA self-management program (OA school) (Thorstensson, Garellick, Rystedt, and Dahlberg, 2015) at a Physical Therapy Rehabilitation Clinic in the

south-west of Sweden. Two persons declined participating without giving any reason and one declined being interviewed a second time due to work. A purposeful sampling, with variations in gender, age and social, anamnestic and rehabilitation background, was recruited (Table 1). The participants were included in OA schools between April 2017 and January 2018. The names of the participants in the article are not their real names. Inclusion criteria were having hip and/or knee OA, going to, participating or having participated in the OA school and being able to understand and speak Swedish. Exclusion criteria were having had trauma, fracture, inflammatory joint or neuromuscular diseases, lumbar spine and/or pelvic pain which surpassed the hip and/or knee pain.

Better care for patients with osteoarthritis (BOA), including OA schools, is a national program in Swedish health care and is, according to the National Board of Health and Welfare, the first choice when treating patients with OA in hip and/or knee. In the OA school, patients are first examined individually by a physical therapist and then invited to group sessions containing self-management education and group exercise training led by trained physical therapists. As part of the first group session, an OA communicator (i.e.

**Table 1.** Some background characteristics for the participants. Peter, Anna, Britt, and Michael were interviewed twice, the two first were pilot interviews (Peter, Anna). The names of the participants in the article are not their real names.

Id	Age	Sex	Marital state	Educational level	Symptom duration	Period	Number of group exercises	Affected joint
<b>Johan</b>	65	Male	Married	Primary school	6 years	20161221–20170330	14	Hip and knee
<b>Per</b>	72	Male	Married	Primary school	6 years	20170222–20170519	23	Knee
<b>Albert</b>	71	Male	Married	Primary school	1 years	20161001–20170131	22	Hip
<b>Lars</b>	69	Male	Married	Primary school	3–4 years	20170222–20170530	20	Hip
<b>Inga</b>	51	Female	Married	Secondary school	2–3 years	20170125–20170216	3 (2 times/week gym)	Knee
<b>Susanne</b>	78	Female	Married	Primary school	1 years	20170426–20170621	8 (1/week)	Knees
<b>Cecilia</b>	53	Female	Partner	Secondary school	5–6 years	20170125–20170424	18	Knee
<b>Peter</b>	64	Male	Married	Secondary school	2 years	20161221–20170215	7	Hip
<b>Anna</b>	61	Female	Married	University	20 years	20161221–20160327	23	Knee
<b>Charlotte</b>	58	Female	Living apart	Secondary school	1 year	20170426–20170722	13	Knee
<b>Alice</b>	65	Female	Married	University	1,5 years	20170118–20170831	11	Knee
<b>Kerstin</b>	51	Female	Married	Secondary school	4 years	20170830–20171231	Home exercise	Hip and knee
<b>Greta</b>	72	Female	Married	Secondary school	10–15 years	Only lectures	0	Hip and knees
<b>Britt</b>	72	Female	Partner	Secondary school	10 years	1. Before intervention 20171012 2. Middle of intervention 20180112	0	Knee
<b>Margareta</b>	78	Female	Married	Secondary school	2 years	20161026–20170116	12	Knee
<b>Michael</b>	69	Male	Living apart	Primary school	4 months	(1) Before intervention	0 13	Hip
						(2) Middle of intervention		
<b>Stefan</b>	71	Male	Married	University	30 years	Before intervention	0	Knee
<b>Monica</b>	69	Female	Married	University	6 months	Before intervention	0	Hips

a former patient with OA who have been trained to teach) discussed how it is to live with OA and shares their own experiences of non-surgical interventions. The OA schools which the participants in this study were attending were conducted in accordance with BOA, but with the following additions: 1) participants had the opportunity to integrate, both in theory and practice for 12 weeks, updated evidence-based facts. These concerned the importance of being physically active, exercise fitness and muscle strength, and avoiding long term sitting in order to reduce the risk of developing comorbidities; 2) participants were offered exercise group meetings with ten to twelve participants twice a week for 12 weeks instead of 6 weeks (Juhl et al., 2014), supervised by physical therapists who continually repeated the evidence-based theory about the importance of being physically active and exercise; 3) in the exercise group meetings emphasis were on exercising fitness and muscular strength; and 4) physical tests (fitness test (Astrand and Ryhming, 1954) and maximum step-up test (MST) (Nyberg et al., 2013)) were conducted at the beginning of the OA school and at follow-ups after 6, 12 and 24 months. For the fitness test, the participants got their own results, the results on group level and the risk for unhealthy in low fitness groups (Kodama et al., 2009).

### **Data collection**

The study has followed the Helsinki Declaration and was approved by the regional ethics committee in Uppsala (Dnr 2017/019). The participants were given both verbal and written information about the study and informed consent was obtained from all. The interviews were conducted in an undisturbed conference room at the Physical Therapy Clinic with one exception that was conducted in the participant's home. Interviews were performed between April 2017 and January 2018, starting with two pilot interviews. As the pilot interviews did not differ substantially from the other interviews they were included in the analysis, making up a total of 22 interviews. To enrich the data according to the emerged themes, four participants were interviewed twice, before and at the end of the intervention (Table 1). All participants read their interviews after they were transcribed and have approved the content. Two participants declined participation in the study without explanation and one declined scheduling for a second interview due to work commitments.

The interviews were mainly conducted by KN and some by MK. The authors (KN, MK) interviewed each other before the data collection began to understand their background knowledge. The authors had no prior

contact with the participants they were interviewing. Their profession as physical therapists was known to the participants. An interview guide was developed containing four thematic areas related to pre-supposed motivational processes for PA and exercise: 1) Experience of participating in the OA school; 2) The role of the physical therapists; 3) Previous experience of PA and exercise; and 4) Future expectations of PA and exercise. These questions were open-ended, according to content analysis (Graneheim, Lindgren, and Lundman, 2017; Graneheim and Lundman, 2004). These open-ended inquiries led to intense interviewing with flexibility to discover new discourses that emerged during the interview. Field notes were taken during the interviews and were used in the forthcoming analytic process. Data collection was terminated after 22 interviews because the aim of variation in demographic characteristics had then been achieved and no new information seemed to emerge according to the aim of the study (Patton, 2015). The interviews were audio-recorded and transcribed verbatim by a secretary. The COREQ 32-item checklist for qualitative studies was used as a checklist to strengthen trustworthiness of the study (Tong, Sainsbury, and Craig, 2007).

### **Data analyses**

A third physical therapist, currently head of a university department within the health sciences with experience of both practical physical therapy and qualitative research, participated in the analysis. Qualitative content analyses with an abductive approach was used to analyze the data, following the procedure described by Graneheim, Lindgren, and Lundman (2017). For a more complete understanding of the data, the abductive approach of moving back-and-forth between inductive and deducted approaches was employed and combined with latent interpretations. To ensure that the analysis stayed close to the data, the authors continuously compared generated sub-themes with "open code data" from the initial manifest coding (Graneheim, Lindgren, and Lundman, 2017).

To gain an overview and a sense of the whole, the authors listened to the audio files and read the transcripts several times with the aim of the study in mind. Data was then analyzed line by the author (KN) forming meaning units containing the participants' descriptions of their experiences concerning motivation for PA and exercise. The computer software Open Code 4.02 was used in the analysis process. The meaning units were condensed into 1716 codes and organized in 13 sub-themes close to the text, still on a manifest inductive level. During the analyses, the meaning units, codes, and

sub-themes were discussed and compared until consensus was reached. Four themes and one main theme on a latent interpretative level were abstracted. For being internally homogeneous and externally heterogeneous the sub-themes, themes, and main theme were compared for differences and similarities (Krippendorff, 2013; Patton, 2015).

## Results

The analyses of the interviews resulted in one main theme; Developing health literacy (HL) to encourage motivational processes for physical activity (PA) and exercise in OA (Table 2). This main theme was built up of four themes: 1) meeting an established self-management program; 2) carrying my life history; 3) understanding the intelligence of the body; and 4) growing in existential motivation. The main theme manifested itself throughout all generated themes and broke through in various sub-themes relating to motivation for PA and exercise in OA.

### *Meeting an established self-management program*

The stories of the participants emphasized that meeting an established self-management program was very important and brought a feeling of being safe, seen and taken care of. The results showed that the prerequisites to form a safe and caring routine was grounded in authentic supportive experts and continuous monitoring. The whole interprofessional team around an OA patient as well as social support were essential for strengthening the motivation to continue with PA for the rest of their lives. By contrast, vague professional interactions and unstructured routines created uncertainty and could inhibit the motivation for PA.

### *The importance of authentic expertise*

Authentic and supportive experts came from different professions and included physical therapists, physicians, nurses, and lay persons who live with OA (OA communicators). Independently of profession it was important that experience and knowledge were shared with authenticity and trustworthiness (i.e. evidence-based knowledge and best practice). The results show the importance of using examples from real life and how much these examples could inspire the participants and give hope about their possibility of feeling better in spite of OA.

*“What really spurred me on was when she [lay person who lives with OA] came here to talk to us. She talked about*

*what she had done and how much better she had got, that was my carrot . . . She convinced me that it works. I was not at all motivated in that way when I was here the first time.” (Peter)*

The participants wanted a clear and decisive attitude from the authentic experts and valued their open and friendly approach. Participants emphasized how a fighting spirit and clear body language could increase a trustful interaction. The experts needed to have deep knowledge, be confident and empathetic, use clear language but still be evidence-based. They should know their own limits and understand when to consult other health professionals (i.e. they should contact a physician when a patient is having signs of heart problems or a psychologist if there were signs of mental illness). The opposite of an authentic expert was characterized as a person with arrogant manners and without concern for other people.

The participants talked over and over again how important it was to be seen and heard by the professionals and to get their attention and support while exercising. They wanted to know if they were doing their exercises correctly and be able to ask questions during exercise. Insecurity could occur when exercising with pain. The participants claimed that not being noticed when they came to the group training affected their motivation to PA negatively.

*“I would have liked the physical therapist to have walked around the room and explained the exercises to us. I don’t even know whether I’m doing it correctly.” (Susanne)*

### *Be part of a well-developed OA routine*

The interviews revealed that being part of a well-developed OA routine was essential to gain new and in-depth knowledge about motivation for PA. It was important to the participants to be examined with care in order to exclude other diagnoses such as tumors. New knowledge broke down old-fashioned thinking about OA, including beliefs that their joints were so seriously impaired that they would break when used.

*“When you’re in the middle of it – you’re in pain or you’re having other problems – then you feel that you are the only one in the world having those problems. But when you join a group like this and notice that there are others who have the same kinds of problems to different degrees and in different ways, then it feels a little better. You get a little more motivated when you hear that other people are training in their own way. It makes you more motivated to do the same.” (Kerstin)*

The participants now understood more about how their bodies were functioning and how the function of joints with OA could improve with PA. The interviews

**Table 2.** Results from the analysis of interviews, concerning motivational processes for physical activity and exercise, with people who attended the self-management program OA school. Examples of quotations forming sub-themes, themes and the overarching main theme. The names of the participants are not their real names.

Main theme: Developing health literacy to encourage motivational processes for physical activity and exercise in OA		
Quotations	Sub-themes	Themes
"He was great//explains really well those basic things so that you really get what it's about. He takes it in the right order." (Michael) 1:16	Encounter authentic expertise	Meeting an established self-management program
"One isn't usually worth more than to be sent home with a schedule./I mean, just getting the chance to come here, it's really something, for me at least. Yes!//I'm worth the investment [laughter]" (Anna) Pilot 1	Be part of a well-developed OA routine	
"Very good [the tests] and they became a sort of carrot for me. I need to change that, I can't have it like this!" (Margareta) 1:15	Monitoring as both carrot and stick	
"I need someone who gives me a real push, someone who's strict with me – you need to do it and you need to do it now." (Britt) 1:14	Individualized social support	
"Yes, hm, I was exercising a lot and I felt sick if I didn't do it. Deep down inside it was probably a way of trying to forget many sad things that were going on at home" (Peter) 1:8	Earlier experiences of being physically active	Carrying my life history
"It's laziness. I do know it's good for me. It was like when I was going to an exercise class with colleagues from work//that was great//if no one else was going, I wouldn't go either" (Charlotte) 1:10	Social norms	
"There's some crap inside that knee moving about./since then I haven't been at all. I don't dare to." (Per) 1:2	Facing OA obstacles	
"If I'm in too much pain, it's like it's telling me that today you need to rest//if I then rest for a day and don't feel the pressure that I have to go outside, then I feel better the next day. One gets to know one's body." (Britt) 1:14	Identifying bodily signals	Understanding the intelligence of the body
"It [the motivation for PA] comes from the upper part of my body in some way/around my shoulders and chest//I get a feeling in my body telling me now I'll do it." (Albert) 1:3	Interpreting bodily-emotional feedback	
"She [a participant] didn't manage, so there was one of you wise people who said to her, try this instead. And she was so happy when she made it//Her whole face lit up. Being able to do something even if you don't do the same as everyone else//that makes it less hopeless" (Alice) 1:11	Building body confidence by daring to challenge one's body	
"I was lying there thinking a lot about how things were going. Would I have to use a walker? I was in so much pain that I could hardly lie on either side. It was terrible!" (Peter) 1:8	Identifying and coping with fear	Growing in existential motivation
"Well before . . . I could be . . . perhaps not quite melancholy but a bit gloomy from time to time, but I don't get like that any more./one effect is that I feel better mentally. Both body and mind belong together, of course, and it feels better in both." (Britt) 1:20	Moving from hopelessness to hope	
"It would mean sitting down in a rocking chair and just rocking back and forth, that one you'd soon read about in the paper, that he had passed away./ . . . /It's dangerous being inactive." (Johan) 1:1	Postponing death	

highlighted the importance of the OA school in which the participants exercised in groups, supervised by physical therapists. To practice what they had learnt and to get individual support and tools for exercising with a painful joint was very important to the participants according to the findings. It was described as essential to challenge oneself to dare to use the painful area of the body. The exercise within the OA school also gave the participants ideas for how to exercise at home and to experiment in finding ways to do the same exercises with home-made tools.

HL and the motivation for PA increased when participants understood the connection between bad physical fitness and the risk of developing other diseases such as cardiovascular diseases.

"The fact that you can get high blood pressure and diabetes is a little scary." (Greta)

The participants talked about decreased blood pressure and healthier diabetes values after PA. Knowledge about OA decreased their worries about the disease and gave them a possibility to better manage their pain. Weight

loss, lower levels of pain and a reduced need for pain killers were other benefits from the OA school observed by the participants. PA increased their self-efficacy and motivated them to continue to exercise regularly.

"Yes, I've continued. I cycle. I put on Spotify when I get up in the morning while the coffee is brewing. [. . .] Then I cycle for fifteen to twenty minutes there and then." (Johan)

Some of the participants did not experience these positive effects; for example, those who got more pain from the exercise, those who were not acknowledged by the experts who led the group trainings, or those who were not feeling socially supported. For some of them, a joint replacement seemed to be the only solution, but this presumption could still be changed.

"Operations can go wrong, and if you were to get worse from that then you may as well just carry on with the exercise. I may need surgery anyway in the end, but then I've at least given it a try. I think I'll be able to cope without an operation for a long time now if I continue to keep up the training." (Peter)

### **Monitoring as both carrot and stick**

The participants experienced the monitoring as spurring them on to exercise more intensely, but it could also make them feel crestfallen or unmotivated with a feeling of hopelessness. The physical tests showed that it takes time to build fitness and strength. Regular monitoring seemed to be a motivating force especially as the retest situation came closer and participants were excited to see whether they had improved since the previous time.

*“The kick I get out of the testing makes it more fun to exercise.” (Albert)*

Being able to trust the physical therapist when being tested was important and gave a sense of security according to the participants. For example, when heart disease was suspected during the fitness tests, the physical therapist immediately contacted a physician for a physical examination.

*“I felt a little dejected, but then I thought about it. He [the physical therapist] really did stress that we had stopped because my heart was beating so fast. Is it because my stamina is so low, I was thinking then. I did feel a little dejected.” (Anna)*

According to the participants this continuous feedback through monitoring strengthened the self-awareness and guided the progress as motivated by both “carrot and stick”. HL also appeared to deepen through bodily experiences.

*“It was a fitness test – catastrophe [laughter] – it felt like a heavy defeat, really tough. I couldn’t even cycle, you know [...] but I gave it a shot and the results from the following test were great. I guess I got a good old kick in the bum.” (Margareta)*

### **Individualized social support**

The participants talked about the importance of social support for them to continue being physically active. Family members, friends, and the opportunity of being a part of a group seemed to have a great impact on exercise habits.

*“I guess it’s possible to exercise on one’s own, but that doesn’t work for me.” (Britt)*

On the other hand, groups could be frightening for some people. Descriptions of social phobia were common in the interviews but also that some liked to exercise by themselves rather than with others.

*“It’s a little hard coming to a place [gym] if you don’t know anyone. [...] I don’t know how to behave.” (Lars)*

Nature, music and dancing were described to facilitate PA. There were outspoken worries about how to stay active and take responsibility for continued exercise after the OA school. Going to the gym alone could be frightening and could become a reason to stop exercising.

Participants who continued exercising in new supportive health promoting groups or with a friend after the OA school described these kinds of social support as very helpful for staying active over time.

*“Exercising isn’t so much fun really. [...] What makes it a little better is that you’re meant to have a training buddy, and that was what I got here. I knew someone at the gym, and the people there have been exercising for three years and they do it in teams. That means you can’t really get away. We try to go on the same days and plan when we meet.” (Albert)*

### **Carrying My Life History**

How the participants were able to carry their life history affected their motivation. They were often hampered by earlier experiences of: 1) being physically active; 2) social norms about PA and exercise; and 3) OA obstacles when participating in the self-management program (i.e. the OA school).

### **Earlier experiences of being physically active**

The stories from the participants’ life histories captured many feelings, positive as well as negative, connected with earlier experiences of PA from an early age until the present day. PA had been performed at elite sports level by some and by others of playing together with friends and family. It was also described as a natural part of an earlier lifestyle. Working hard on a farm in childhood or having to ride a bike or walk longer distances to be able to play with friends made some of the participants used to physical efforts at an early age. PA was often connected with playing or recreational sports, such as football, skiing, being in the forest, playing different games or picking berries and mushrooms.

*“There was always something going on. We were climbing trees and jumping in hay ... There were no computers in those days.” (Albert)*

PA could, according to the participants, be a way to manage anxiety and depression rather than being a source of joy or fun. Some described PA as a way of escaping a dysfunctional family situation and that they fled from home into nature where they walked around or jogged for hours. In nature they found peace and safety.



*“I found reassurance in nature [...] escaped a lot of trouble at home that way.” (Michael)*

PA was described to be addictive and could result in negative effects such as anorectic behaviors. For these participants, exercise became poisonous and was affecting their lives destructively. Other negative memories of PA appeared when describing exercise in school, including not being chosen by classmates for group exercises, not being physically strong or able to perform in different sports or feeling ashamed of one's body.

*“It was something I just had to do. I know it will get better if only I'd get there, that's how it's always been. Just like in the '90s, when I used to train a lot. I was outside running four days a week every week. I was running fifteen or five kilometers a week. It lasted for three or four years. I was running all the time. It didn't matter what the weather was like, if it was cold, raining, snowing. Yes, it was something I just had to do, a kind of poison.” (Lars)*

Exercise was also described as getting boring after a while which was a reason why it could be hard to stay active. Pain, illness, and bad weather also made it difficult to stay motivated to exercise. On the other hand, pain could in some cases be a part of exercising that one was used to and therefore not a barrier to PA.

*“I've played both ice hockey and football so I know that exercise hurts.” (Albert)*

The results reflect a wide variety of experiences of PA that seem to impact on motivation and thereby on the development of HL.

### **Social norms**

According to the participants, social norms in relation to PA had been formed in their childhoods, by their families and the surroundings where they grew up. Happy memories when the whole family were skiing together or seeing mothers and fathers always working hard became role models and inspirators for PA. Another important reason for being physically active was the social norm of being good-looking, and this seemed to be a very strong motivator.

*“Well, there's that barrier, I don't want to get fat!” (Inga)*

Social norms also influenced the view of other people and their relation to PA, especially people who do not exercise. These people were described as fat, lazy, and lacking responsibility for their well-being. The descriptions of these people suggested that they would let others do the job and gladly sit looking on. Lazy people were compared with alcoholics that do not accept help.

*“Oh but don't you recognize them, those comfortable people who haven't got the time to help others or do their bit? They'd rather get a piggy back.” (Johan)*

To be physically inactive was associated with shame, guilt and with the existential feeling of being unworthy.

*“If I didn't exercise I'd get very disappointed with myself.” (Anna)*

The participants also claimed that time had changed and that children of today are sitting still in front of their computers instead of being outside playing as they had themselves done as children. Another observation was that the social norm of PA had changed over time. For example, training with weights in a gym was earlier regarded as a bit silly whereas now it is a common way of exercising.

### **Facing OA obstacles**

The results show several different physical experiences of OA that limit activities and become barriers for motivation for PA. OA pain was described in different ways by the participants. It could be pain in the night, cramps, stabbing, or described as a feeling of “concrete” in the knee. The pain could be distracted by immersive experiences such as “I don't feel pain when I am spending time with my grandchildren” or “I don't feel pain when exercising”. Unpleasant experiences included “lockings”, not being able to “trust the resilience” in the joint or a sense of instability.

Comorbidity factors such as heart disease and diabetes were described to reinforce the barriers against staying physically active. According to the participants these experienced barriers needed to be confronted to achieve HL and enhance motivation for PA.

*“The post box was two hundred metres away, so I took the bike because it hurt too much to walk [...] but with the help of the rubber bands and a bit of cycling and so on, well [laughter] yesterday I walked round the lake, three kilometres as a matter of fact, to the tip of the headland.” (Johan)*

### **Understanding the intelligence of the body**

According to the participants the body and its signals, here highlighted as the theme understanding the intelligence of the body, could contribute to a strengthened HL. Being able to identify and interpret body signals gave the participants a new way of handling sensations and information from their bodies, consciously and with an increased knowledge which resulted in decreased fear. Pain signals were met with knowledge that the participants gained from the OA school instead of self-

made ideas of what was happening to their painful joints. They expressed that they also learned to react to emotional body-feedback in a healthier and more conscious way compared to before they participated in the OA school. In summary, these skills guided the participants into new habits and behaviors by building body confidence through daring to challenge their bodies.

### **Identifying bodily signals**

The participants described that when they started to listen to their bodies and its signals and learned how to interpret them, they gained an increased knowledge about their own bodies. They expressed that they became more aware of what the different signals represented and they started to listen to their bodies instead of ignoring or being afraid of the signals. This generated a feeling of increased understanding and trust toward their own bodies and they were, for example, able to challenge the pain instead of avoiding it. On the other hand, the participants also expressed that it could be very difficult to understand the signals of the body, especially in relation to pain.

*“It does hurt [...] but it’s when I can feel that cork screw ... it’s not arthritis I’m quite sure of it.”* (Per)

How to be physically active with the pain present and how to interpret the signals of pain was described as difficult, very challenging, and also frightening.

*“One really has to learn that it isn’t dangerous to move about. One thinks that one can’t move, because then the knee will break.”* (Cecilia)

### **Interpreting bodily-emotional feedback**

The results confirmed that the body expresses emotions sited in the body in different dimensions – physical, psychological, and existential – which give feedback to body and mind. Thereby the body constantly reminds us that we need to move and also how and how much. The participants described that they felt restless in their bodies if they were sitting still for too long. This resulted in a feeling of decisiveness to, for example, go for a walk or exercise. The decisiveness could be felt in the head, shoulders, chest, or any other place in the body and seemed, according to the participants, to be an individual experience.

*“I get stiff in both head and body from sitting still”* (Anna).

Signals such as feeling worry in the stomach and creeping in the legs were often described by the participants.

The narratives also described dealing with mental illnesses such as anxiety and depression through PA. Exercise gave reward immediately through feelings of comfort and calmness in the body and mind.

*“That uneasy feeling in my stomach [...] disappears when I do this [exercise] [...] Then the anxiety disappears.”* (Susanne)

To be able to grasp and interpret bodily emotional feedback seemed to affect motivation for PA and the development of HL.

### **Building body confidence by daring to challenge one’s body**

Reading between the lines, it became clear that bodily confidence was being developed in parallel with this HL process. The participants seemed to get a stronger and deepened HL by daring to challenge the pain during exercise. The participants learned to acknowledge and manage the pain in order not to overload the joint with too many repetitions or weights that were too heavy. There seemed to be a fine line between listening to one’s body’s signals, ignoring them or being afraid of the pain.

*“I don’t feel well when I’m sitting still, I really don’t. So sometimes it can all get a bit much perhaps, pulling in all directions. I don’t know, perhaps I take on too much. [...] I don’t stop to feel whether it’s hurting.”* (Margareta)

Participants who learned to understand the intelligence of the body through physiological and emotional signals seemed to interpret them in relation to their gained knowledge and experience which supported them in their everyday lives.

*“In the beginning it was hurting. The first few times that I was cycling the pain got worse, but then it gave way [...] Now I cycle quite a lot [...] and can walk the stairs more easily.”* (Cecilia)

### **Growing in existential motivation**

The results comprised a deep existential dimension here described as dealing with one’s human existence in relation to motivation for PA. Coping with fear was essential in their progress of HL. The participants also had feelings of hopelessness transformed into hope when achieving a sense of meaningfulness in everyday activities as well as setting goals in a lifetime perspective. Finally, this existential power was grounded in a feeling of postponing death.

### Identifying and coping with fear

Fear both drove and hindered motivation to be physically active in the participants' narratives. In this sub-theme the focus was on fear connected with existential motivation, i.e. fear that was described to have to do with deep emotional feelings, such as the fear of losing contact with family and friends or the fear of death.

*“To be stuck in a wheel chair and get dependent on everyone else [...] disconnected from the surrounding world.” (Anna)*

The risk of losing functions because of OA and to be left having to sit still, unable to move and therefore losing one's freedom, was described in terms of a nightmare. The participants expressed that they were afraid of losing their identity and their faith in the future.

*“The future – there's none really [...] I've been talking to all my mates and it's just downhill from here.” (Per)*

### Moving from hopelessness to hope

To be injured or having pain could make you end up outside social groups and could be connected with a feeling of hopelessness and loneliness which could affect life on an existential level and the person's HL long term. According to the results, PA and exercise give hope for the future when transferring PA into meaningful everyday living.

*“Before, I couldn't get my leg over the motor bike, it wasn't possible. Now I can heave it over. It's incredible!” (Peter)*

Being in nature, playing with grandchildren and traveling with friends were shaping an existential identity, according to the participants. They described themselves as thinking more highly of their own bodies and becoming more exuberant. Participants who had increased knowledge and insights about OA were able to turn to existential goals with a healthier lifestyle and they described that they had gone from hopelessness to a faith in the future.

*“Sometimes when I'm feeling my worst I think about what would happen if I were to get sick and unable to do anything. But at the same time the grandchildren are telling me – grandpa, you mustn't get sick, you're going to live to be a hundred, they say.” (Lars)*

There were several stories about how knowledge and increased insight about OA, a better understanding about one's own capacity together with access to concrete tools had strengthened the participants' physical ability to gain independency. When the participants recognized improved physical function, they gained

hope on a deeper, existential level by understanding that they could, for example, avoid or decrease pain medication and/or operations.

### Postponing death

The long-term existential life goals had a deeper meaning for the participants and could be summarized as postponing death. They wanted to have as high quality of life as possible. To be independent, fit and have fun while aging and for as long as you live motivated PA. Postponing death seemed to be a very efficient motivator for staying physically active, more essential than experiencing PA as enjoyable.

*“Yes, what's the driving force ... well, it's that one's getting older and one wants a good life to live and not lie in bed, barely able to move.” (Peter)*

Tears and sadness were expressed during the interviews when it came to the loss that pain had led to, but also happiness when the exercise improved function and reduced pain. The participants were often able to regain function which meant they could live their lives more fully. A woman described how existential motivation drove her to continue exercising to be able to continue playing with her grandchildren.

*“I want to stay at this level [...] I have a young grandchild and want to be able to stay with her for as long as possible.” (Britt)*

The existential process of motivation was described as swinging between hope and hopelessness, unconsciousness and consciousness, and between meaningless and meaningfulness.

*“The clock is ticking and you get older [...] I want to slow down that development as much as possible.” (Stefan)*

### Discussion

The overarching latent theme in the present study of motivational processes for PA turned out to be developing health literacy (HL) in motivational processes for PA and exercise. This includes themes of authentic expertise, life history, the intelligence of the body and existential motivation with an underlying theme of postponing death. Thus, in physical therapist practice, exploring HL in relation to PA and exercise in OA seems essential for disease prevention and health promotion. For ensuring the transferability, the generated themes need to be explored among patients from other countries and cultures.

An integrative conceptual model of HL referring to knowledge, motivation, and competences of accessing, understanding, appraising, and applying health-related information within healthcare, disease prevention, and health promotion settings, respectively, is needed (Sorensen et al., 2012). In the present study, a well-established management program seems to play a crucial role for raising HL. To support motivation for PA and exercise the integration of a person's life history, the intelligence of the body and existential motivation seem to be important.

The present results show the essential support provided by a well-established self-management program where the individual participant meets professional experts. The value of these kinds of extrinsic facilitators is confirmed in several systematic reviews of barriers and facilitators concerning PA in OA published in the last 10 years (Dobson et al., 2016; Kanavaki et al., 2017; Marks, 2012; Petursdottir, Arnadottir, and Halldorsdottir, 2010). These earlier studies, as well as the present study, show that lack of support and professional knowledge can become barriers for PA and exercise. However, the present results illustrate a deeper understanding of a need for authentic experts, which means that the professional authenticity is essential to facilitate motivational aspects in HL. The expert should have evidence-based knowledge, be trustworthy, be empathetic and able to see the individual, and have a fighting spirit and clear body language. Monitoring functional improvements functions as both carrot and stick and has also emerged as an important aspect.

In line with Dobson et al. (2016) the present study highlights that experiences of PA and exercise affect attitudes and exercise beliefs important for motivation and behavioral maintenance. The novelty of the present result is showing the relevance of widening the perspective and understanding people's life histories concerning PA and exercise. The life histories might entail dark experiences including using PA and exercise to cope with mental illness, anxiety, escaping from dysfunctional families, and in connection with anorexia. Furthermore, according to the present results, it seems important to acknowledge that PA and exercise can be a "trigger" of unpleasant memories.

OA is not just a joint disease sometimes symptomatic with persistent pain and joint impairments. Research illustrates that psychological distress like anxiety and depression are common comorbidities (Sharma, Kudesia, Shi, and Gandhi, 2016). OA is a condition that can affect the whole person and their identity and therefore needs to be treated with a biopsychosocial perspective according to EULAR recommendations

(Geenen et al., 2018). Kanavaki et al. (2017) supported the significance of biopsychosocial caring when treating patients with OA. Miller et al. (2016) highlighted the importance of targeting OA as a chronic health condition and, in order to improve a person's quality of life, shifting the health system from acute episodic models to one that meets the needs of the individual. In line with the present results, a person needs to understand how their life history affects attitudes to PA and exercise and find ways to confront or take advantages of these attitudes.

The present study conceptualizes two dimensions essential for physical therapy, namely the importance of the intelligence of the body and the existential approach to achieve a deeper interaction between motivation and HL, namely existential motivation. Cott (1995) early described in her Movement Continuum Theory of Physical Therapy that physical therapists have the key to be able to incorporate physical and pathological aspects with social and psychological dimensions through movement. Physical therapists have a special opportunity to guide patients to use what in the present study has been described as the intelligence of the body. Participants in the present study described fear of signals from the body; for instance "it feels like a 'corkscrew' inside the knee when I try to walk" or as "something will break".

It seems important for people suffering from OA to lift the signals of the body to a conscious level to develop the dimension of motivation in HL. Earlier qualitative research in physical therapy and persistent pain has presented this in a sub-theme called "developing greater understanding of the body signals" (Nordström, Ekhammar, and Larsson, 2020). Other physical therapy interventions such as Basic Body Awareness Therapy (Gyllensten, Skar, Miller, and Gard, 2010) also intend to involve the whole person and their movement characteristics experiencing the body from the inside and becoming familiar with one's body's signals (i.e. physical, psychological, physiological and existential). To confirm the signals of the body, and strengthen the connection of awareness and emotions, these sensations and experiences transform into a greater understanding of their own bodies. This can hereby possibly strengthen motivation for PA which is in line with the theme "understanding the intelligence of the body" in this study. Van der Maas et al. (2015) suggested that understanding the signals of the body and the emotions, especially negative ones, could decrease catastrophizing and thereby might decrease kinesophobia and increase self-efficacy. To use already known concepts in physical therapy also when treating people with OA is an interesting aspect especially as research has found perceived

self-efficacy as crucial for the maintenance of PA after a period of supervised training (Hammer, Bieler, Beyer, and Midtgaard, 2016).

Finally, the emerging theme of existential motivation is found to be a deeper component throughout the process toward increased PA and exercise. By helping the patients to really understand what gives them meaning in their everyday lives or what will make them fulfill their dreams seem to have an unspoken impact on motivation. When we are broken or vulnerable it seems easier to reconsider life. Thereby physical therapists have great opportunities within their professional roles to facilitate existential profound thoughts and use this underlying power into motivation for PA and exercise while at the same time develop stronger HL.

The findings of this study show that existential motivation such as “exercising to postpone death” have a deep impact on people’s motivation. According to hope theory, there is hope in such a life-orientated existential goal even if there are parallel emotions of fear triggering this process (Snyder, 2002). Fear as a trigger for behavioral change and for maintaining motivation has earlier been suggested in osteoporosis (Hjalmarson, Strandmark, and Klässbo, 2007). Thereby, in line with this study, it seems to be important to guide persons with chronic OA pain to go from hopelessness to hope despite fear and transform fear as at trigger.

Moreover, the present core results illustrate how the different dimensions of motivation are interacting in the development of HL for PA and exercise in OA. HL expresses the need for knowledge, competence, and motivation to achieve healthy behavior. This is in line with how self-determination theory highlights various aspects of competence, relatedness, and autonomy to interfere in motivational processes to achieve behavioral change and maintenance. The generated concept of existential motivation might here be a key to facilitating relatedness according to self-determination theory (SDT) (Ryan and Deci, 2000). To really go deep and make the person express their existential drive for PA and exercise and thereby relate the goal in an existential way seems to have great impact according to the present findings. Physical therapy goals such as raised muscle strength or joint movement only become secondary goals when the focus is on values that raise a person’s existential identity; for instance, being a well-functioning grandmother or relating one’s identity of being a nature-loving person to actually spending time in the forest.

Trustworthiness is a major concern in qualitative research and can according to Graneheim et al. (Graneheim, Lindgren, and Lundman, 2017) encompass

transferability, dependability, credibility, and authenticity. To reach multiplicity for significant variations in data and to strengthen the transferability, this study was based on in-depth interviews with people with different background variables and with a variety of life histories (Patton, 2015). Richness in data was generated as the interviews were allowed to take as long as they needed to for the participants to think deeply and speak freely (Krippendorff, 2013). The interviews were conducted by two physical therapists with long experience of both clinical practice and qualitative research. The transcribed interviews were sent to the participants and they had the opportunity to correct and confirm the content.

To strengthen the dependability, three physical therapists conducted the analysis. In the analysis, there was an interplay between quotations and codes using the data program Open Code. In order to further ensure the credibility and authenticity, the generated themes were compared with data repeatedly, by all three main researchers, and discussed until consensus was reached. The whole interprofessional research group made their contributions to the study design, aim, method, results, and discussion, which was important to strengthen the trustworthiness of the results. Weaknesses of the study could be that the two persons who conducted the interviews were both physical therapist and stationed on the same physical therapist unit. This was also the unit where the physical therapists that were involved in the OA schools were based. These were all things that the participants knew. The authenticity might have been threatened as the informants could have had problems expressing negative opinions about the interviewers’ colleagues.

The participants in this study have attended a somewhat modified OA school in which the importance of being physically active and exercise aerobic fitness and muscle strength in order to reduce the risk of developing comorbidities were highlighted; 12 weeks instead of 6 to 8 weeks of exercise supervised by physical therapists were offered (Juhl et al., 2014); aerobic fitness test (Astrand and Ryhming, 1954) and a new maximal step-up test (Nyberg et al., 2011) with follow-ups were conducted. This can have affected the motivational processes of the respondents.

It is very important to define the role of a physical therapist when discussing the results of the present study of reaching patients on a biopsychosocial and existential level. The possibility of grasping all of these dimensions can be perceived as overwhelming for one category of health profession (Alexanders, Anderson, and Henderson, 2015). Research has found that some patients with persistent pain should be treated in

multidimensional teams where physical therapists make up one in the team (Geenen et al., 2018).

Interesting questions emerge when analyzing the results. Does every single person need a whole theme of caring professionals around them? The results of the present study show that it differs a lot between the interviewed participants. Some need no support, and some need a lot of support to be physically active and motivated. Perhaps the use of some kind of instrument could help to assess attitudes toward and/or capabilities regarding OA self-management as early as possible in the rehabilitation process (Eyles et al., 2017).

The present study has been conducted in a Scandinavian context and to ensure the transferability of the results, the generated themes need to be explored among individuals from other countries and cultures. Previous research has not actively included aspects of the intelligence of the body or existential motivation. Therefore, it would be interesting to direct future research on these aspects and through controlled design follow the motivational process and PA of this target group. The exercise program at the OA school should integrate learning processes to develop the intelligence of the body even stronger than the current program. The program could focus on existential drivers, in addition to other biopsychosocial aspects that have shown good effect in other research (Dobson et al., 2016; Kanavaki et al., 2017; Marks, 2012; Petursdottir, Arnadottir, and Halldorsdottir, 2010). To implement the results from this study, the OA schools and the physical therapists involved in these interventions, must incorporate motivational processes with focus on understanding the interplay between carrying one's life history, developing bodily intelligence as well as growing in existential motivation. Continued research on motivational processes in OA could be to: 1) do a systematic review where the new aspects from this present study concerning the intelligence of the body and existential motivation are included; 2) develop a clinical guide for future behavior-orientated implementation research; and 3) use this guide in controlled and process-oriented evaluations to better understand the impact of a motivation-oriented approach to OA.

## Conclusions

When people with OA in their hip and/or knee come to OA schools the physical therapists must ask them about their motivation for being physically active and to exercise. Questions can be asked about their life history in relation to PA and exercise in order to confront motivation. Knowledge about the signals of the body connected to OA should be implemented in the OA schools in

order to help people live a good life despite OA while coping with the symptoms. Growing in existential motivation guide people to mirror fears, hopelessness, and hope in transforming profound driving forces into the reality of exercising to postpone death.

In summary, meeting an established self-management program, carrying one's life history, the intelligence of the body and growing in existential motivation are essential for developing health literacy in motivational processes to encourage the maintenance of physical activity and exercise in osteoarthritis.

## Notes

1. Registered physical therapist, specialist in orthopedics, with long experience of working with people with OA and with research experience of both quantitative and qualitative methods.
2. Registered physical therapist, specialist in pain and pain rehabilitation, with long clinical experience mainly within primary care and with experience of qualitative research.
3. Registered physical therapist with long clinical experience and with research experience of both quantitative and qualitative methods.

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