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Abstract

Purpose: Physical activity (PA) is increasingly being used in hospice care as a rehabilitation strategy to help patients manage symptoms and improve quality of life. However, little is known about how to design and deliver interventions that promote uptake and maintenance of PA in this population. Single-level approaches (i.e., psychological models) have primarily been used to study factors that influence PA engagement among patients with advanced, incurable disease and therefore offer a limited perspective on strategies that target changes beyond the individual level. This study explored perspectives on factors perceived important for influencing PA participation in hospice care using a social-ecological framework. Method: Patients' (n=27) and health providers' (n=5) from multiple hospices (n=5) across the UK were involved in this study. Data were collected using focus group and individual semi-structured interviews and analysed using a thematic framework approach. Results: Eight main themes were perceived to be important for influencing PA engagement at the individual, interpersonal, physical environment, community, and policy levels including: (1) PA as therapy; (2) apprehension about PA induced harm; (3) group based PA with peers; (4) supervised PA sessions; (5) limited facilities and access; (6) patient-centred approach; (7) lack of a strong PA culture and; (8) absence of a policy and guidance for PA provision. Conclusion: Hospice-based PA interventions that target multiple levels simultaneously may be more effective at successfully changing and sustaining patients' PA behaviour. Study findings provide evidence-based recommendations that may facilitate effective delivery of PA interventions in hospice care.

Keywords: Exercise, palliative care, behaviour change theory, qualitative research

Physical activity in hospice care: A social ecological perspective to inform policy and practice

Within the UK, hospice care services provide support to approximately 200,000 patients with advanced, incurable disease every year (Hospice UK, 2016). By 2040, this number is expected to rise by 25-47% as a result of an ageing population (Etkind et al., 2017). Consequently, demand on hospice care resources will rise significantly in the next few decades (Bone et al., 2018). Moreover, the scope of hospice care provision has recently expanded whereby hospices now provide support to patients throughout the course of the incurable disease trajectory rather than simply bereavement/end-of-life care (Gomes & Higginson, 2008). This shift in the focus of care has resulted in the adoption of a rehabilitative approach, which includes multidisciplinary care (i.e., medical, psychosocial, physical and spiritual therapies) to patients and their families including physical activity (PA) provision (Javier & Montagnini, 2011; Paltiel, Solvoll, Loge, Kaasa & Oldervoll, 2009).

PA is a cost-effective, non-invasive adjunct therapy that can address the complex needs of patients with advanced, incurable disease (Malcolm et al., 2016). Evidence is building around the efficacy of PA as a symptom management intervention (Albrecht & Taylor, 2012; MacDonald, 2009). For example, studies show that regular PA can help improve physical health outcomes (i.e., pain, fatigue, shortness of breath, insomnia, functional mobility, and cardiorespiratory/musculoskeletal fitness) in selected patients (i.e., outpatients) (Oldervoll et al., 2006). Importantly, there is preliminary evidence to suggest physical fitness is a major factor determining life expectancy and quality of life in this population (Eyigor & Akdeniz, 2014). Psychologically, PA has been found to improve patients' levels of stress and depression (Kumar & Jim, 2010). Moreover, qualitative studies reporting patients' perspectives indicate that PA can enhance positivity, improve physical self-perceptions, distract from disease-related concerns, instil a sense of belonging and connectedness, foster social support, and empower patients to self-manage their disease (Malcolm et al. 2016; Paltiel et al., 2009). PA interventions are increasingly being used within hospice care including the adoption of group models of delivery, which can respond to the needs of a growing number of outpatients (Belchamber & Gousy, 2004; Turner, Tookman, Bristowe, & Maddock, 2016). However, there are no current recommendations or guidelines specific to the delivery of PA in hospice care. Currently we know little about how to design effective PA interventions that are accessible, enjoyable, and inclusive to all patients regardless of disease type, prognosis, and performance status (Lowe, Watanabe, Baracos, & Courneya, 2012). There is a clear need for PA evidence-based recommendations that meet the needs of a diverse palliative patient population. One way of gathering evidence that can inform practice is to use a social ecological approach.

Social ecological models (SEM) to PA interventions recognize that individual behaviour is influenced not only by individual characteristics but also by the sociocultural contexts in which individuals reside (Boulton, Horne, & Todd, 2017). Factors within various domains/levels of influence can interact and/or reinforce health behaviours (Sallis, Owen, & Fisher, 2008). Various SEM models (e.g., Sallis, Owen, & Fisher, 2008) have been developed to map out these levels. McLeroy et al.'s (1988) model is commonly used in public health contexts and includes the individual (i.e., knowledge, attitudes, beliefs, self- efficacy, age, and gender), interpersonal (i.e., social networks and social support systems including family, friends, peers, and co-workers), organizational (i.e., rules, regulations, and informal structures of organizations and institutions), community (i.e., education and community regulations and norms), and policy (i.e., local, state, national, and global policies, laws, and procedures) levels. Currently we know little about factors, beyond the individual/interpersonal levels (e.g., fear of movement, social support; Mas, Ninot, & Xavier, 2015), that may influence the uptake and maintenance of PA among patients with advanced, incurable disease.

SEM models suggest that consensus building (i.e., actively engaging with the target population to design, implement, and evaluate health interventions) is integral to the process of identifying targeted strategies at multiple levels. In this study, we involved multiple key informants (i.e., hospice patients and health providers) to explore their perspectives on the delivery and uptake of PA in clinical practice. The purpose of the study was to explore factors deemed important for influencing PA participation within hospice care using an adapted version of McLeroy et al. (1988)'s socio-ecological model.

Methods

A qualitative descriptive approach (Sandelowski, 2010) was used to identify factors that can facilitate and prevent PA engagement within hospice care. Qualitative description provides a comprehensive summary of a phenomenon in everyday language by interpreting data in ways that remain close to verbatim accounts and subjective meanings of participants (Sandelowski, 2010). It involves a process of low-inference description to data analysis, which allows for data-derived answers to questions relevant to practitioners and policy makers (e.g., how to promote PA within hospice care). Qualitative description has been used to study complex and understudied phenomenon in health science research (Colorafi & Evans, 2016). It was used in this study to provide a description of patients' and health providers' shared views on PA within hospice care. This study was framed by ontological relativism (i.e., reality is multiple, created, and mind-dependent) and epistemological constructionism (i.e., knowledge is constructed and subjective).

Participants

Participants were recruited using a purposive maximum variation sampling strategy in order to capture a diverse range of views (Sparkes & Smith, 2014). The sample consisted of 32 participants including 27 outpatients and 5 health providers. The majority of patients were female (63%) and primary diagnosis was cancer (78%) (see Table 1). Health providers included occupational therapists (n=2), physiotherapists (n=2), and a consultant (n=1) (see Table 2). Inclusion criteria included: (1) patients with an advanced, incurable disease currently attending a Sue Ryder hospice; (2) Sue Ryder clinical staff currently providing direct care to patients with an advanced, incurable disease and; (3) 18 years or older. Patients lacking capacity to consent or deemed too ill to participate in this study (as per the judgement of Sue Ryder clinical staff) were not invited to participate in this study.

Study procedures

Ethical approval was obtained from both the North West - Greater Manchester West Research Ethics Committee and the Sue Ryder research governance group. Five Sue Ryder sites (i.e., hospices) agreed to take part in the study. A member of the clinical care team at each local site was identified to help with participant recruitment (i.e., patient identification and initial contact). Participants were recruited between February to October 2017. The last author (LM) conducted the focus groups and individual interviews with participants. Recruitment of participants continued until data saturation was achieved. That is, an iterative process of collecting and analysing data was used until nothing new was being learned and data started to repeat what was expressed in previous data (i.e., informational redundancy) (O'reilly & Parker, 2013). At this point, a conscious decision to end recruitment occurred based on a preliminary stage of analysis. Data saturation therefore operated at the level of the dataset as a whole helping to ensure that a comprehensive and meaningful interpretation of participants' perspectives on factors that may impact PA engagement at multiple levels of influence was generated (Green & Thorogood, 2009). All participants completed a consent form.

Data collection

One focus group interview with hospice patients (n=5-6) and one individual interview with a health provider (n=1) were conducted at five Sue Ryder hospices across the UK. Given the vulnerable patient population and potentially sensitive topic of the research, semi-structured interviews were used. Interviews have been found to: (1) result in beneficial effects (e.g., therapeutic, empowering) for palliative patients and their carers (Gysels, Shipman, & Higginson, 2008); (2) build rapport and foster reciprocity between the interviewer and interviewees and; (3) can adjust to participants' level of understanding ensuring sensitive use of open questions and appropriateness for discussion. All interviews took place in a private room located at the hospice. For convenience to the patients, the focus group interviews were arranged to coincide with their scheduled hospice visit. Prior to the start of the interview, patients and health providers were given further study details and the opportunity to discuss their participation. Interviews were audio recorded using digital Dictaphones. An interview guide was used to help facilitate discussion. Focus groups with patients included questions such as: 'What are your opinions and views on PA for patients receiving hospice care? Individual interviews with health providers included questions such as: What are your views and opinions on PA for patients receiving hospice care? And, what do you think are the benefits/challenges of implementing a hospice-based PA intervention? Follow-up questions using clarification, elaboration, and detail orientated probes were used to elicit richer data.

Data analysis

Data were analysed deductively utilising a framework method (Richie & Spencer, 1994) whereby data were reviewed for content and coded for correspondence to the five hierarchical levels of the SEM (i.e., individual, interpersonal, physical environment, community, policy). A framework (i.e., progressive tabulation) was used to provide a new structure for the data in order to answer the research questions in the form of codes/categories, sub-themes and themes generated from the data (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Analysis progressed through four steps. First, the interviews were transcribed verbatim (all identifying details were removed from transcripts) and each transcript was read and reread to get an overall sense of the data. Second, descriptive codes were generated by engaging in a process of line-by-line labelling of text segments. This step involved indexing, whereby the first author identified sections of the data that corresponded with the five levels of the SEM. Third, similar codes/categories were grouped together into subthemes and entered into a framework matrix – one for patients and one for health providers. This step then involved charting (i.e., moving the data from its original textual context and placing it in the framework). Fourth, a collaborative process that involved working with critical friends (Smith & McGannon, 2018) occurred whereby alternative explanations for findings that were generated were suggested and discussed with the research team. A thick description of each theme was developed with supporting quotations selected from the original transcripts to build a complex, holistic picture.

Study rigor

Study rigor was guided by a relativist approach (Sparkes & Smith, 2009) whereby a list of criteria based on the work of other researchers (e.g., Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2016; Tracy, 2010) was used as a starting point to judge the quality of this study. The list included: (1) rich rigour, which was achieved by collecting data from multi-informants (i.e., patients and health providers) to build a comprehensive understanding of factors influencing PA participation in hospice care. Using this strategy enabled new or deeper insights to be generated from multiple perspectives and facilitated complementary views and opinions; (2) fidelity to the subject matter, which occurred by eliciting data from patients and health providers in their natural setting (i.e., at the hospice day therapy unit) in order to achieve authentic closeness to the phenomenon under study; (3) transparency, which occurred whereby the interviewer [LM] practiced conscious reflexivity, used a reflexive journal, and consulted with critical friends [SB & AU] (Smith & McGannon, 2018) throughout the process of data collection and analysis; (4) coherence, which was evidenced throughout the process of triangulation of data whereby the lead researcher [SB] explored how patient focus group data and health provider interview data overlapped, contradicted, and enabled more complex understandings to be created (Flick, 2018) and; (5) exploiting exceptional data whereby the process of data analysis involved attending to outliers (Phoenix & Orr, 2017) and integrating contradictory data into core themes through a process of juxtaposition and contrast.

Results

Multiple factors within different levels of the social ecological model were identified as salient for the promotion of PA within hospice care for patients with advanced, incurable disease. The following eight main themes and 30 subthemes (see Table 3 for a list of themes and subthemes) were identified. Main themes included: PA as therapy, apprehension about PA-induced harm, group-based PA with peers, supervised PA sessions, limited facilities and access, patient centred approach, lack of a strong PA culture/infrastructure, and absence of a policy and guidance for PA provision. Verbatim quotes are included in the main text below to provide supporting evidence.

Individual level

2 main themes related to individual factors were identified, which reflect the underlying attitudes, motivations, and beliefs that influenced both patient and health providers' perspectives of PA behaviour within hospice care. The first main theme, PA as therapy, reflects participants' perceptions of the physical and psychological health benefits of PA participation. The second main theme, apprehension about PA induced harm, reflects participants' worries and concerns related to PA participation.

PA as therapy. Participants believed that PA could help them to manage their disease and treatment-related symptoms and side effects. PA was also believed to be beneficial for preventing future health problems such as physical decline and deterioration (e.g., cachexia) associated with their condition.

> Interviewer: What are the potential benefits of engaging in PA?
>
> Patient: It's [PA] all about my muscles really. Just trying to keep them moving, keep them working. And maintaining what I've got, improving potentially what I've got. So then you get a bit more longevity out of them as things start to go, really go (Patient 1, hospice 1, focus group)

From the perspective of health providers, patients were seen to be motivated to engage in PA to preserve (or improve) their current level of functional mobility so they can continue to perform accustomed functions and activities of daily living. Health providers also spoke about the adverse physical consequences (e.g., sarcopenia, infection susceptibility) associated with too much time spent sedentary and its negative impact on patients' physical health and prognosis:

> We know it [being in bed or being still] deteriorates you much quicker. You are more susceptible to infection. And that you decondition, not only your muscles but your heart, and your lungs. And it changes your prognosis quite dramatically (Health provider, hospice 2, one-to-one interview)

Although health providers believed that PA was beneficial for improved health, concerns were voiced around the need for care when presenting the importance and benefits of PA so it is not overestimated by patients as a cure for their illness/disease:

> It's almost like they [patients] think that it's [PA] going to provide the answer and it's almost like a cure or something that's going to change the direction of the disease. And it will never do that. But it will maintain the quality of life, and it will probably maintain their functional ability. (Health provider, hospice 5, one-to-one interview)

PA was also deemed important for patients' psychological well-being by helping them to feel like they were being proactive in self-managing against progressing disease. PA was seen as a way for patients to take control over their health: "You [the interviewer] were just asking Jim about the physical and mental benefits of PA and I was going to add that I think for me when I do the exercises there's a huge mental benefit because I feel like I'm doing something. I'm not sitting there and rotting. I'm doing something to stop the rot." (Patient 1, hospice 2, focus group). Patients also discussed the importance of engaging in activities that helped to distract themselves from adverse consequences of their disease such as pain, fear, and worry. Activities that fostered a singularity of focus by helping patients to absorb themselves in the task at hand (e.g., Tai Chi) were deemed beneficial for experiencing respite from the disease. Overall, PA was believed to be positive as it was seen as a therapeutic strategy for preventing and managing physical and psychological health concerns.

Apprehension about PA-induced harm. Patients conveyed that they wanted to be (more) active but noted that PA posed a risk of physical harm (i.e., injury, falls, and overexertion) and were worried that it could exacerbate disease and treatment-related symptoms (e.g., fatigue, pain). A foremost concern was causing further damage to their already fragile body. For example, the long-term consequences of incurring an injury because of PA was worrying:

> Interviewer: Most of you have spoken about your concerns related to breathlessness. Are activities that target breathlessness important to you?
>
> Patient: Yes but you don't want to do anything that's going to put you back. You don't want to pull a muscle, or you have to stop moving altogether on that muscle because that would be detrimental long term (Patient 2, hospice 1, focus group)

Patients were also cautious about engaging in PA because of the consequences of getting themselves into awkward and difficult situations that they wouldn't be able to self-manage (e.g., unable to get up after a fall).

Health providers also noted their concerns related to PA because patients were susceptible to injury and harm (e.g., fractures) due to muscle weakness, lack of flexibility, postural instability, and motor control difficulties. There was concern that the potential for physical harm could result in prolonged rehabilitation periods, an inability to recover from a setback, and a greater risk of dependence, and exacerbation of symptoms. Health providers noted the importance of implementing safety measures and appropriate exercises for patients:

> We had one lady who was doing exercises, and was coming to day therapy once a week and was doing too much. So the impact on her in terms of her pain and her fatigue and her breathlessness all had quite a significant impact. Then by overdoing it, she didn't want to continue to do it because she thought it was harmful. If we would have had it [exercise] at the right level and at the right grade, then actually we could maybe have built up a little bit, and it could have been of benefit (Health provider, hospice 5, one-to-one interview)

In addition to feeling apprehensive about the possibility of physically harming themselves, PA was viewed to have a potential detrimental impact on the psychological well-being of patients. Both patients and health providers spoke about how PA could act as a reminder of their declining condition and cause distress if they could no longer engage in it:

> Interviewer: Is there anything else that PA gives you?
>
> Patient: It can be great in terms of your self-esteem but it can also have a flip side. I went swimming recently and I used to be able to do front crawl and now I can't do that anymore and it's just like 'well you know the things that you could do a few months ago' (Patient 1, hospice 1, focus group)

Overall there was apprehension about PA engagement because it could potentially lead to physical and/or psychological harm.

Interpersonal level

Two interpersonal factors were identified, which depict patients and health providers' perspectives on social factors that can influence PA participation in hospice care. The first main theme, group based PA with peers, depicts participants' views on the multiple benefits of participating in PA with other patients with advanced, incurable disease. The second main theme, guidance by trained specialists, reflects patients and health providers' views on the importance of supervised hospice-based PA sessions for facilitating PA participation.

Group-based PA with peers. Patients discussed the benefits of group-based PA with peers. In particular, they reported a preference for participating in PA within groups comprised of fellow patients with advanced, incurable disease because being surrounded by people who weren't diagnosed with advanced, incurable disease (and were perceived to be healthy and fit) reinforced health disparities and contributed to experiences of psychological ill-being:

> Interviewer: Can you tell me about your preferences when it comes to participating in PA? Is it important to exercise in a group or on your own?
>
> Patient: I try doing upper body and stuff like that by myself and I feel kind of stupid and not motivated really. (Patient 2, hospice 3, focus group)
>
> Patient: That's the one thing with this group is that nothing is stupid (Patient 1, hospice 3, focus group)
>
> Patient: Well nobody minds because we have done some daft things here [at the hospice] (Patient 2, hospice 3, focus group)
>
> Patient: If you haven't done it your going do it [daft things] (Patient 4, hospice 3, focus group)

> Patient: Yes, but everybody has a giggle about it but you're not being laughed at for doing something that is different from what other people can do. So even doing Pilates sitting on a chair. If you went to a normal class, because I did go to one at one point when I was in better condition. I wanted to keep up with them but I couldn't. Nobody laughed at me but I was not coping with what everybody else was doing and I felt bad about that. (Patient 5, hospice 3, focus group)

Group based PA with peers was seen as a way to help patients feel more confident to participate in PA. It was also deemed instrumental for helping patients work through physical discomfort and not give up when faced with hardship:

> Interviewer: Can you explain any benefits you may have gained as a result of participating in the exercises classes offered here [at the hospice]?
>
> We try harder (I think) when we're together because we know we're all going through the same thing… (Patient 2, hospice 2, focus group).

Group-based PA was also deemed important for promoting a sense of camaraderie, enjoyment, social interactions, and social support. Patients noted that it provided opportunities for them to interact with one another: "This [group-based PA] is a huge, a huge important part for me. Just to have camaraderie. To have people to talk to and get out of the house so." (Patient 1, hospice 3, focus group). Along with fostering peer social interactions, health providers noted that alongside fostering peer interactions, group-based PA also provided peer support: "They're in the group because it gives them peer support. And that encouragement from being a group, and feeling like they have their own support as well as having us." (Health provider, hospice 2, interview). Participating in group-based PA with peers was viewed as important for engaging in PA. It was seen as a way for patients to feel socially accepted, increase motivation, experience camaraderie and enjoyment, and give and receive peer support. However, one patient expressed a dislike for group-based activities in general as he preferred to engage in activities on his own.

Guidance by trained specialists. Patients commented on the importance of PA sessions being supervised by health providers. Trained staff who could select appropriate exercises and provide guidance on how to do exercises correctly were perceived to be important for instilling confidence in patients. Patients also wanted supervised PA sessions so they could get support if any problems arose during PA. Guidance by trained professionals promoted a sense of safety and reduced fears associated with participating: “And if it [collapse] happens you’re in great hands you know. Yeah, you’re in the best place**”** (Patient 1, hospice 3, focus group). “Someone will get you off the floor” (Patient 5, hospice 3, focus group). Instruction by professionals was also seen as important for preventing harm:

> Patient: You need to know, as I said before, from a medical perspective what is possible and if you can attain that target. (Patient 2, hospice 1, focus group)
>
> Interviewer: And is that why sometimes gentler forms of movement/exercise feel more appealing because the risk feels minimised?
>
> Patient: Yes that takes away the worry about “well should I?” Because as long as I know that that [exercise] is something I can do. I’d just like to be shown [from a trained instructor] how to do it. So then you’re not going to hurt anything else. I think that is the almost the first step. (Patient 2, hospice 1, focus group)

Trained health professionals were also seen as important for encouraging patients to participate in PA. They were seen as an importance source of motivation for ensuring that patients started exercising, completed their exercises correctly, and sustained participation.

Physical environment level

One main theme related to the physical environment was identified. Limited facilities and access reflects participants’ views on the difficulties of accessing hospice-based PA opportunities due to limited transportation. It also depicts health providers' desire for more PA equipment and dedicated space.

Limited facilities and access. Participating in regular PA was difficult for patients because of limited access to PA sessions offered at the hospice. Patients relied on transportation to the hospice in the form of taxis or lifts from family/friends. Health professionals also noted that a lack of transport to the hospice was a common barrier to regular PA participation for patients:

> Some of the patients wanted to attend my exercise class last week and they couldn't get here because a lot of them can't drive. They can only use their friends and their relatives so much in a week. And so they have to prioritise…We are quite a way out in the sticks. There's no sort of shuttle bus running. So it's got to be a private car or private taxi. (Health provider, hospice 3, one-to-one interview)

Health providers talked about wanting to offer more opportunities for patients to engage in hospice-base PA. A lack of specialized equipment (e.g., medimotion bikes, gym equipment, hydrotherapy pools), and dedicated space were barriers that prevented local hospices from delivering more PA opportunities:

> And also it's the environment as well, so having somewhere to do it. We are really short on rooms and space and private space. I think it's about resources and time and people to do it really. And people with the kind of expertise really to do it. (Health provider, hospice 1, one-to-one interview)

Organizational/community level

Two factors related organization/community were identified, which centred on the delivery and content of PA within the hospice setting. The first main theme, patient centred approach, represents the importance of delivering PA that is respectful of, and responsive to, patients' personal needs and preferences. The second theme, absence of a PA culture refers to a lack of a PA infrastructure within the hospice.

Patient-centred approach. Health providers noted that patients' performance status and activity levels varied significantly, ranging from being bed-bound to fully active. Patients varied significantly in their ability to execute particular sensorimotor actions (e.g., walking, bending, lifting, rolling) and covered a diverse range of symptoms including loss of muscle power and bulk; weakness and tiredness; breathlessness, poor balance; and pain. For these reasons, both patients and health providers discussed the importance of PA being adapted and individually tailored:

> I think it has to be personalised to the person's needs. And their health and their condition. And you know obviously if somebody had breathing issues you wouldn't potentially do too much aerobic work. Or if somebody's got a risk of a pathological fracture you probably wouldn't put too much pressure on that bone. So there are certain things that you'd have to be aware of definitely. (Health provider, hospice 1, one-to-one interview)

Patients commented on their preference to take part in PA within a setting that was flexible and fostered autonomy. It was important for patients that PA was delivered in a way that facilitated choice so they could adapt the type, duration, frequency, and timing of PA in order to suit their ability and energy levels. Patients wanted to feel like they had liberty to adjust movements or opt in and out of the PA sessions as they deemed appropriate.

Patients were motivated to engage in PA if they believed it would help them manage the adverse consequences of their condition. They conveyed a preference for engaging in personally meaningful goal-directed therapeutic activities that could help them manage a specific symptom (e.g., breathlessness). For one patient, motivation to participate in PA (and other types of therapies) was driven by a desire to rebuild functional mobility:

> Interviewer: What are people’s opinions on the role of PA at this particular time in your life?
>
> Patient: I want to be able to get down to the shops. I want to be able to get around Sainsbury’s on my own. I would do activities that somebody tells me “this is good, this will get you walking better.” I mean I things like, tai chi is meaningless to me. The only thing I’m interested in is doing things that are going to get me walking better (Patient 6, hospice 2, focus group)

Gentle types of physical activities that were uplifting and soothing for both the mind and body such as tai chi, pilates, yoga, walking, dance, stretching, and light resistance training were identified. Health providers also discussed the importance of adopting a gentle approach to PA sessions. Moreover, a gradual and progressive build up to PA was deemed crucial when prescribing PA in order to prevent fatigue and delayed onset muscle soreness.

Absence of a strong PA culture. Most participants expressed that the hospice lacked a strong culture of PA. In particular, patients felt that they lacked awareness and information on what different types of activities they should be doing, how to overcome PA related barriers, how much activity to do, and how to stay motivated. They wanted more professional advice on what was appropriate for them considering their health status:

> Interviewer: Are there any activities that help you experience gains or make you feel like you are pushing yourself more than you are doing now?
>
> Patient: It’s actually very difficult because when the consultant guy tells me at the hospital that my heart is only working 20% of its capacity, which sends alarm bells ringing I’m not actually sure what I should be doing. And what I shouldn’t be doing anyway. I think that is a problem (Patient 3, hospice 1, focus group)

Patients also expressed a desire to engage in PA at the hospice and wanted more opportunities to be active: “…the only criticism I would have is that it doesn’t happen often enough here.”

(Patient 2, hospice 2, focus group). Overall, most participants believed that the hospice lacked a strong culture of PA. They wanted the hospice to embrace a PA infrastructure that permeated the day-to-day delivery of health care. However, hospices varied in terms of their PA delivery whereby some hospices provided more opportunities than others.

Policy level

One factor, absence of a policy and guidance for hospice-based PA was identified at the policy level. This main theme reflects a lack of continuity and consistency of PA provision within hospice care.

Absence of a policy and guidance for PA. Health providers expressed the desire for more PA education around PA delivery and services, more trained staff or time/hours to alleviate patient demand, structured roles and responsibilities, and increased funding so PA could be integrated more widely and consistently into the care pathway. They felt it was important that PA was integrated into the care services offered to patients so that they had regular access to varied and sustained PA opportunities. Some health professionals were concerned that not all members of the patient care team believed that the promotion of PA was their role. Moreover, concerns were raised that PA wasn't built-in to routine practice:

> I think theoretically it's [PA] given quite a high priority. When patients come in [to the hospice] it's one of the key areas that's always assessed. But it could be better followed through than it is, if you see what I mean. And that's partly through staffing, with all the things I've mentioned already. But…yeah it's just somehow getting it into routine practice (Health provider, hospice 4, one-to-one interview)

When patients were asked about what physical activities they currently or regularly do, they talked about their disappointments related to a lack of consistent PA provision:

> Patient: You were quite upset when you couldn't go anymore, weren't you Janet? (Patient 5, hospice 4, focus group)

> Patient: Yes. I went there [Manorlands gym at Airedale hospital] for about 14 weeks. I absolutely loved it. I got so much from it and I felt really good. It was my favourite [begins to cry] sorry, sorry… I wanted to keep going [still crying] but I'd had my quantity of lessons…my quantity of visits and then I had to make way for other people which is fair enough. (Patient 1, hospice 4, focus group)

Discussion

The purpose of this study was to explore factors deemed important for influencing PA participation in hospice care from the perspective of both patients and health providers. The study was framed within the SEM (McLeroy et al.,1988) to help identify influences on PA engagement at multiple levels (e.g., organizational, policy). Findings provide support for the SEM and suggest that PA behaviour may be impacted not only by psychosocial factors but also the wider context and setting in which PA occurs. We recognize that this study could have adopted a different theoretical perspective (e.g., theory of planned behaviour, self-determination theory), which may have identified different factors that influence PA behaviour in the context of hospice care. However, SEMs have been used to assist in the development of programme design because they target multiple levels simultaneously, and therefore are more effective at successfully changing and sustaining behaviour than single-level approaches (Sallis, Owen, & Fisher, 2008). Employing the SEM in this study was novel and was useful for facilitating a better understanding of the antecedents of good practice for the delivery of PA programmes within hospice care. It also enabled us to provide a solid foundation from which to develop suggestions for implementing policy guidelines. The discussion below will consider the findings at each level and implications for practice.

At the individual level, PA was perceived by patients and health providers as a therapeutic strategy to prevent future health problems and manage existing physical, functional, and psychological conditions. This finding is consistent with previous quantitative and qualitative research, which has found that PA (e.g., strength, flexibility, balance, and aerobic exercises) in palliative care can manage distressing symptoms (e.g., fatigue, pain, depression) and maintain or slow down functional decline (Oldervoll et al., 2006; Lowe, Watanabe, & Courneya, 2009). Overall, participants believed that PA was beneficial and viewed it as an important component of hospice rehabilitation. Drawing on self-determination theory (Deci & Ryan, 2008), motivation for PA can originate from extrinsic sources (i.e., when behaviour is driven by external factors) and/or intrinsic sources (i.e., when behaviour is driven by the task itself). The participants in this study seemed to be motivated to engage in PA for primarily extrinsic reasons (i.e., to gain health benefits and avoid negative health outcomes). This finding supports research with older adults, which has found that health is a strong predictor of PA levels and can be either a motivator or an impediment to PA (Costello, Kafchinski, Vrazel, & Sullivan, 2011). Given that intrinsic motivation is arguably the most stable motivational component for sustaining PA participation (Deci & Ryan, 2008), it might be important to design hospice-based PA programmes to help patients not only manage health outcomes (extrinsic motivation) but also derive pleasure and satisfaction inherent from PA itself (intrinsic motivation). This could be achieved by ensuring that PA is appropriate, stimulating, and inherently enjoyable.

Participants in this study were apprehensive about engaging in PA. Risk of injury, fear of falls, and concerns related to worsening their existing condition were identified as factors that may potentially deter a substantial number of patients with advanced, incurable disease from participating in PA. Findings support research with advanced lung cancer patients, which found that patients avoid engagement in PA when they feel anxious about experiencing pain or harm (i.e., kinesiophobia) (Mas, Quantin, & Ninot, 2015). In this study, it is possible that patients' apprehension toward PA stemmed from a lack of confidence in their ability to engage in PA (i.e., reduced physical self-efficacy) without experiencing bodily harm. Studies show that physical self-efficacy is an important psychological factor that not only influences the initiation and maintenance of PA but also other activities that aid recovery after renal transplantation (Zelle et al., 2016). The adverse physiological and psychological symptoms (e.g., pain, breathlessness, stress) associated with advanced, incurable disease and its treatment may result in low physical self-efficacy levels hindering patients' involvement in movement based activities. Hospice-based PA programmes should be designed to increase the physical self-efficacy levels of patients to help them become more confident in their ability to engage in PA without causing added bodily harm. For example, assistive devices (harnesses, treadmills) may alleviate patients concern around falling.

This study also suggests that PA engagement may result in patients reflecting on their past PA experiences, which could hamper their motivation and enjoyment for PA. Engagement in PA may make patients cognizant of their declining condition through negative comparisons of present (i.e. perceptions of how their body currently functions) and past (i.e. perceptions of how their body functioned prior to their diagnosis) PA abilities. A perceived discrepancy may lead to experiences of negative affect. In this study, patients seemed to frame perceptions of their body post diagnosis through performance-based physical function standards (i.e. restrictions in what they were no longer physically able to do). It may therefore be important to adopt a PA delivery approach that promotes and cultivates patients' interoceptive awareness of their body (i.e. an internalised knowing of the body perceived through sensation) (Garfinkel et al. 2015) to encourage a heightened understanding of how their body feels. In shifting patients focus away from an exteroceptive awareness of their body (i.e. a knowing of the body provided through external stimuli) patients may become less reliant on markers in the external environment as a means of comparison and measurement of their performance and experience heightened body satisfaction.

Group-based PA (e.g., circuit classes, seated Pilates) has been found to foster social interactions, support, camaraderie, and motivation among palliative cancer patients and patients with mixed diagnosis (Malcolm et al. 2016; Paltiel et al. 2009). The current study provides support for these findings and highlights participants' preference for group-based PA. It also extends the work in this area by showing that group-based PA may foster perceptions of social acceptance, which might be an important motivating factor for participating in PA within the hospice. Considering that patients often feel misunderstood and experience a sense of loneliness (i.e., lack of psychological connectedness with other 'beings') (Nyatanga, 2017), group-based PA with peers may be an important model for delivery within outpatient services. Participating in PA with small groups of patients (e.g. 10 or fewer) may counter feelings of alienation by helping patients foster relationships where they feel not only supported but also acknowledged and embraced. Importantly, positive social interactions (e.g., social support) have previously been found to help patients cope with terminal illness (Belchamber, Gousy, & Ellis-Hill, 2013; Sand, Olsson, & Strang, 2009). Drawing on social-relational theory (Kuczynski & Parkin, 2007), PA engagement may be influenced by bidirectional processes that occur during socialization (e.g., between patients and patients and health providers). For example, study findings support the suggestion that supportive interactions (e.g., guidance, encouragement, assistance) between advanced cancer patients and their health providers is perceived to be an important factor that facilitates PA involvement by helping patients work through barriers to PA (Burke et al. 2015). Health providers are uniquely positioned to educate patients about the benefits of PA, address fears, and promote interventions in this population.

Patients at end-of-life report high levels of physical inactivity (Oldervoll et al., 2006), possibly due to barriers in their physical environment. Research has found that structural barriers (e.g., inadequate facilities) can hinder older adults PA involvement (Bethancourt et al. 2014). The participants in this study reported limited transportation, lack of specialized PA equipment and dedicated space as potential barriers to regular PA involvement. A key finding from this study was that both patients and health providers wanted the hospice environment to be more PA friendly. In particular, they expressed a desire for infrastructural improvements to support safe, appropriate, effective, and convenient PA for all patients. Structural support for patients with advanced, incurable disease is crucial as patients may face added difficulties from those patients diagnosed with early stage disease in regards to the amount of effort, planning, and preparation required to engage in PA at the hospice (e.g., make special arrangements for transportation, limited functional mobility requiring specialized equipment). Future research should consider investigating the impact of environmental factors (e.g., dedicated space) on the uptake and maintenance of PA. For example, specialized equipment that encourages PA might be required in hospices in order to prevent high levels of sedentary behaviour and inactivity. Hospices may want to consider including suspended harness systems that support the practice of balance and walking tasks; activity tracker devices (e.g., Fitbits) that can monitor, assess, and provide PA feedback; electromechanical aids such as virtual reality systems and robotic devices that can simulate movement, reduce physical discomfort, and encourage independent involvement in PA. Moreover, modern PA rehabilitation environments need to provide places within the hospice that enable opportunities for PA (Duff, 2011) by, for example, identifying environmental modifications that invite more walking (Andrews, Hall, Evans, & Colls, 2012).

Study findings suggest that a patient-centred approach to the delivery of PA may be important for facilitating the uptake and maintenance of PA involvement within hospice care. Our findings confirm those of previous research, which found that a patient-centred PA intervention increased the PA levels and satisfaction of inactive patients diagnosed with advanced staged lung cancer (Bade et al., 2018). Tailoring PA to patients' functional ability may be important for fostering patients' physical self-efficacy by ensuring that PA is feasible and targeted at the appropriate level of intensity and duration. This can be achieved by training health providers to deliver PA using a differentiated approach (i.e., modified versions of exercises). Differentiation is the foundation of good pedagogical practice in PA and if done well can facilitate access, opportunity, is motivating and is more likely to result in adherence to the activity. This is important for ensuring that classes appeal to those who may want to physically challenge themselves and those who prefer light activity. Moreover, in line with self-determination theory (Deci & Ryan, 2008), patients expressed a desire to exercise autonomously during PA sessions, by being able to control when and how they participated. It might be important for patients with limited functional mobility to feel like they can self-manage their exercise participation by opting in and out of PA sessions as they choose. Further investigation of the role of autonomy in PA and advanced, incurable disease is warranted.

Patients and health providers shared the view that the hospice care system lacked a strong culture of PA that included consistent PA delivery (assessment, personalized prescriptions, monitoring, information about available PA programmes). This finding supports the research conducted with oncology and palliative care consultants, which found that advanced cancer patients look to them for PA recommendations and that there was a need for more information on providing PA advice (Sheill, Guinan, Neill, Hevey, & Hussey, 2018). Patients in this study wanted evidence based recommendations about how to safely start or continue regular PA and more knowledge of the benefits of PA. An organizational commitment that prioritizes a culture of PA within the hospice setting may be crucial for incorporating PA programs as routine treatment. When health providers and those in a position of responsibility regularly communicate the importance of PA and incorporate a supporting infrastructure it subsequently becomes part of the hospice identity. Implementing a hospice-based PA policy (and outlining a framework describing how hospice PA will be promoted and delivered) instils the value of this lifestyle behaviour to the healthcare mission. Formalizing a policy also sets an expectation for management support, which can help foster a new habit of physical activity within hospice care. Future work in this area should be underpinned by qualitative policy implementation research, which can make important contributions to the future design of efficacious PA policy legislation.

In considering the implications of this study, the extent to which the findings may apply to other patient populations (e.g., inpatients) receiving hospice-based care and/or other contexts (e.g., hospital, home) where palliative care is delivered to patients is unknown. However, it is quite likely the findings extend beyond both the outpatient population group and hospice setting. For example, the themes *limited facilities and access to PA opportunities* as well as *absence of a policy and guidance for PA* apply not only to outpatients who access specialist care at most Sue Ryder day therapy units but also in-patients who remain in hospice for longer durations while receiving care. Thus, this study displays a form of naturalistic generalization (Smith, 2018) whereby some of the current findings may well apply beyond the outpatient hospice care population group. It may also generalize through transferability whereby some of the study findings may be transferable to other palliative care settings such as hospitals and home care.

Limitations

There are limitations of this study that should be considered. First, the sample consisted of day therapy/outpatients who accessed the hospice for a range of services. Study findings therefore represent only one subpopulation within hospice care. Different themes and subthemes may have been produced if inpatients, who are at a later stage in the disease trajectory, were included in this study. Second, the study sample is comprised of patients diagnosed with primarily advanced, incurable cancer (80%). The hospice population is diverse and represents a wide range of disease types. Study findings may therefore represent primarily the voice of those patients living with cancer.

Conclusion

Multiple factors at different levels of influence (e.g., interpersonal, community, policy) need to be considered when promoting and delivering PA in hospice care. It is important to continue advancing our understanding of patients' and health professionals' perspectives of rehabilitation strategies that may help improve patients' quality of life at end of life. From an applied perspective, hospices should consider implementing a PA care pathway that includes assessment of patients' PA levels, brief advice/education, personalized prescription, and signposting to hospice-based PA opportunities. This highlights the importance of evidence-based recommendations that can help guide the delivery of PA within hospice care.

What Does This Article Add?

1. Knowledge on factors at multiple levels of influence that impact on PA engagement in hospice care.
2. Patient and health provider perspectives on the design and delivery of hospice-based PA.

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