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Exercise is Medicine? Most of the time for most; but not always for all

Dr Toni L. Williams*

Institute for Sport, Physical Activity & Leisure, Leeds Beckett University

Emily R. Hunt & Dr Anthony Papathomas

School of Sport, Exercise and Health Sciences, Loughborough University

Professor Brett Smith

School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham

*Address for corresponding author: Fairfax Hall 202, Headingley Campus, Leeds
Beckett University, Leeds, LS6 3QS, UK

T.L.Williams@leedsbeckett.ac.uk

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Institute for
Sport, Physical
Activity & Leisure

Exercise is Medicine? Most of the time for most; but not always for all

Based on extensive research on the relationship between exercise and health, exercise as a form of medicine is a powerful concept of growing popularity within healthcare, academia and policy. Proponents of this exercise is medicine (EiM) movement frame exercise as a panacea for a variety of health issues and uncritically promote exercise as good for all. Two clinical populations particularly influenced by the EiM agenda are spinal cord injury (SCI) and arthritis. The purpose of this research was to explore how individuals with SCI and arthritis personally make sense of their exercise experiences. Data were collected through semi-structured interviews with 10 participants with SCI and 20 participants with arthritis. Following a thematic narrative analysis, three patterns were identified across the whole data set. These were: 1) exercise and restitution; 2) exercise and pain; and 3) exercise and pleasure. Taken together, these results provide new knowledge regarding the impact of exercise that both align with, and contrast, the dominant EiM discourse. When exercise is perceived as ‘medicine’, stories of exercise participation spoke of cure, and restitution, rather than health and well-being. Pain was an unwelcomed side effect of exercise participation for some, and had a detrimental impact upon motivation and engagement. Lastly, a focus upon the medicinal benefits of exercise did not reflect the multiple pleasures experienced through exercise participation. Thus, health professionals, academics and policy makers need to prescribe to more ethical forms of exercise promotion that may lead to more efficacious, person-sensitive interventions.

Keywords: exercise is medicine, clinical populations, restitution, pain, pleasure, ethics

Introduction

‘Exercise is Medicine’ (EiM) is an ongoing and expanding global health initiative committed to the belief that promoting physical activity (PA) is integral in the prevention, management and treatment of disease (Lobelo et al., 2014). Since the launch of this initiative, the *EiM* slogan has become a powerful discourse within academic, medical and policy circles (Cheng & Mao, 2016). Based on the established relationship between exercise and physical health, the EiM movement specifically calls upon healthcare providers to prescribe PA as a means to control a wide variety of clinical health issues (Pedersen & Saltin, 2015; Sallis, 2015). Proponents of this movement also duly call upon individuals to take responsibility for their health and become more active for their own good (Berryman, 2010). In line with a neoliberal health role, the EiM initiative thereby ignores any societal aspects of sport and exercise participation leaving the individual solely accountable for being physically active (Malcom, in press; Smith & Perrier, 2015; Williams et al., 2014). Furthermore, the pervasiveness of the EiM movement has led some to conceptualise it as an emerging *dominant narrative* that tells a story of improved health and well-being through continued engagement in PA (Papathomas et al., 2015). From this perspective, the phrase ‘exercise is medicine’ is not passive but rather has the capacity to act on people. Some argue that it has evolved from a powerful metaphor into an unmitigated fact, whereby exercise IS medicine and it is accepted wholly and uncritically as such (Malcom, in press).

There are attendant dangers associated with a scientific enterprise that adopts a dogmatic allegiance to a given concept, especially when said concept is as complex, uncertain and morally contested as the relationship between exercise and health. Dogma reinforces orthodoxy of insight (Howe, 2009) and can block the criticality inherent in many scientific philosophies; from Popperian empiricists (Rowbottom, 2011) to cultural interpretivists (Schinke & McGannon,

2015). It is rare for a concept to reach canonical status at the speed at which EiM appears to have done; particularly when there is evidence to suggest that exercise may actually not be medicine – or at least not always. Not all non-communicable diseases respond to exercise; either in terms of prevention or treatment (see Dodd et al., 2010). Further, the EiM movement’s position that exercise is ‘good’ for everybody, demonstrates a reluctance to acknowledge the possible negative side-effects of participation (Malcom, in press). The party line is toed unquestioningly to the extent that researchers and policy makers ignore, or perhaps forget, that exercise can present negative consequences (Nesti, 2016).

Some researchers have suggested the abundance of support for EiM actually addresses efficacy and implementation effectiveness rather than real-world treatment effectiveness (Beedie et al., 2016). The essential argument here is that it matters not whether exercise is medicine if few are prepared, or able, to engage with it. Given less than a third of global populations meet the recommended PA guidelines¹ (Hallal et al., 2012; Katzmarzyk et al., 2017) this is a genuine concern. The positive messages conveyed about the medicinal benefits of exercise appear to have had little impact on participation. This paradox regarding physical (in)activity has been hailed by Ekkekakis and Dafermos (2012) as ‘one of the most frustrating phenomena in public health’ (p.198). In light of this, some exercise scientists have questioned whether taking a medical model approach is the most effective way to promote exercise (Cheng & Mao, 2016). For example, Smith (2016a) contends that reducing exercise to ‘medicine’ limits our broader understanding of the exercise experience. Essentially, exercise can be medicine but it can also be so much more. Therefore, a more holistic approach should be undertaken to enable academics, health

¹ Physical activity guidelines provide information regarding how much aerobic and strength exercise is required per week for people to stay healthy or improve their health. The UK guidelines can be found here: <https://www.gov.uk/government/publications/uk-physical-activity-guidelines>

professionals and policy makers to envisage both the benefits and negatives of engaging in exercise.

Two clinical populations particularly influenced by the EiM agenda are spinal cord injury (SCI) and arthritis. In terms of SCI, EiM has been identified as the preferred meta-narrative in relation to exercise within rehabilitation and community settings (Williams et al., 2016). A wealth of literature associates exercise in SCI populations with improved psychological well-being (Williams et al., 2014), reduced risk of comorbidities (Buchholz et al. 2009), and improvements in fitness and cardio metabolic health (van der Scheer et al., 2017). Similarly, exercise is touted as crucial to pain relief and the preservation of mobility in those diagnosed with osteoarthritis (OA) or rheumatoid arthritis (RA) (Demmelmaier et al., 2015; Kelley et al., 2011). Exercising with arthritis is also associated with better mental health (Gettings, 2010), with physically active individuals reporting increased self-efficacy and improved mood (Demmelmaier et al., 2015).

We do not question the plethora of research supporting the benefits for health and well-being associated with exercise for SCI or arthritis. However, we do propose that the homogeneity of exercise-related experiences presented in this extant literature, within and across these two populations, is at odds with interpretively informed inquiry which attends to nuance and complexity. Much of this research is the result of (post)positivist approaches which seek to confirm an existing hypothesis; that exercise *is* medicine. Within this paradigm, natural biopsychosocial mechanisms are foregrounded, and sociocultural processes shaping exercise experiences linger in the background, or remain positioned as part of one's social psychology (Fullagar, in press). This does not make such findings wrong or irrelevant but it does suggest they tell just one side of the story; how exercise benefits a given condition. In contrast,

interpretive qualitative approaches allow for an exploration of how individuals personally make sense of exercise within the various contexts of their own lives. Without a priori theories leading the research, individuals are free to construct the impact of exercise on disability according to personal experience – be that positive or negative – rather than according to the tenets of EiM. With these principles in mind we aim to address the following research questions: 1) How do people with arthritis and SCI experience exercise following injury and illness? 2) How do stories of exercise resonate with, or contest, the EiM discourse?

Methodology

Narrative is a form of psychosocial inquiry that focuses on one specific genre of discourse: a story. Humans have been widely accepted as storytellers, and therefore this forms an underlying assumption that humans lead *storied lives* (Papathomas, 2016). For example, people express themselves through stories and make sense of their lives and experiences by telling stories. Furthermore, people transmit *meaning* by telling stories, and understanding meaningful experience is a central component of narrative inquiry (Frank, 2010). Stories are of importance to this study because they are a key means by which people make sense of their lives following illness and injury (Frank, 2013). There is also a strong emphasis in narrative analysis on human lives being culturally and relationally constructed (Smith, 2016b). In addition, narratives are not only resources for telling personal stories; they are also actors as they *do* things on, in, for and with us (Frank, 2010). In other words, narratives are crucial actors in helping *create* and *shape* experience through the ordering of events. Stories have the capacity to *act* in a way that guides and informs our actions and future possibilities (Smith, 2016b). Therefore narrative analysis allows us to focus on the personal stories of participants with SCI and arthritis whilst also exploring how these stories may have been shaped by dominant discourses surrounding health

and exercise. In line with these characteristics, narrative inquiry falls within an interpretivist paradigm, framed by ontological relativism (reality is perceived to be multiple, malleable and subjective) and epistemological social constructionism (knowledge is assumed to be socially constructed through relational interactions) (Papathomas, 2016).

Sampling and Participants

Following university ethical approval, a purposive criterion-based sampling strategy was used to recruit people with SCI and arthritis who had experiences of PA. This type of sampling targets people of a clearly defined group who have experienced the same phenomenon (Sparkes & Smith, 2014). This level of analysis across data sets makes a significant contribution to the literature on PA-enhancing interventions and recommendations to PA policy and practice for disabled populations (see Martin Ginis et al., 2016; Williams et al., 2017). That said, we are mindful of the important conceptual difference between impairment (injury/illness) and disability. In this study we adhere to a social relational understanding of disability. Through this lens, disability is conceptualised as a form of *social oppression* experienced by people with impairments in the face of social restrictions on activities, aspirations and psycho-emotional well-being (Thomas, 2012; Smith & Perrier, 2015).

The participants with SCI were all involved in a novel exercise programme known as activity-based rehabilitation (ABR). The aim of ABR is to maximise an individual's physiological, functional and neurological potential, and improve the health and well-being of people with SCI through intensive exercise (Jones et al., 2014). Initial contact was made with the participants via an email from staff at the ABR centre. If any clients were interested in taking part then they were provided with a participant information sheet including contact details of the research team. In total, 10 participants with SCI took part in the study. The participants varied in

terms of their age (20-52 years), time since injury (1-28 years) and time participating in the exercise programme (1 month – 2.5 years).

Participants with arthritis were recruited as part of another study that explored exercise experiences and arthritis. Initial contact was made with the participants via arthritis charities and social media. If people were interested in taking part they contacted the researcher and were sent the information sheet and consent form. Participants reported to be physically active but were not currently involved in an exercise intervention or PA programme. In total, 20 participants with arthritis took part in the study. Participants varied in age (24-79 years), length of diagnosis (6 months-36 years) and arthritic condition (OA, RA, psoriatic arthritis, Ankylosing spondylitis) with two participants diagnosed with more than one type of arthritis.

Data collection

Before any data collection commenced, the aim of the project was explained again and participants were given the opportunity to ask any questions. Ethical procedures were followed as participants were informed of their rights through the informed consent process. All of the participants were involved in a semi-structured interview that lasted between 60 and 170 minutes. Semi-structured interviews were used to explore participants' PA before their SCI or onset of arthritis and their PA experiences following injury and illness. The purpose of the semi-structured interview was to create a conversation that invited the participants to tell stories about their insights, feelings, experiences and behaviours in relation to exercise (Smith & Sparkes, 2016). To illicit narrative data and the telling of stories, participants were encouraged to 'tell me a story about being active with arthritis/SCI'. Each interview was transcribed verbatim and saved on a password protected computer.

Narrative analysis

In line with our research questions, we conducted a thematic narrative analysis. This type of analysis focuses on the *whats* of storytelling by scrutinising the stories for core patterns and central themes (Smith, 2016b). During transcription, initial thoughts about the life story of each participant were noted. Next, a period of indwelling was undertaken through reading the transcripts to become familiar with stories of each participant and to begin thinking *with*, not just *about* stories (Frank, 2013). The data was then coded and initial themes were explored within each individual story. Questions such as ‘What are the implications of this theme?’ and ‘What are the assumptions underpinning the theme?’ were asked to help explore the connections between codes and themes (Sparkes & Smith, 2014, p.133). In comparison to other types of analysis that focus on identifying patterns (e.g., thematic analysis and interpretative phenomenological analysis), thematic narrative analysis focuses on central themes in *stories*, rather than in all or any talk (Smith, 2016b). With this in mind, narrative themes were identified as patterns and common threads that ran through each story, and thematic relationships were examined across stories from people with arthritis and SCI. Throughout this analysis, authors worked together to act as ‘critical friends’ encouraging reflexivity regarding exploration of alternative explanations and interpretations (Sparkes & Smith, 2014).

Results and Discussion

Through the process of thematic narrative analysis, three themes were identified in the data across both SCI and arthritis populations. These were: 1) exercise and restitution; 2) exercise and pain and 3) exercise and pleasure. These three patterns provide new knowledge regarding the impact of exercise on the lives of those with SCI and arthritis that both align with, and contrast, the dominant EiM discourse. We now define each theme through a joint results and discussion section to integrate participant quotes with analytical interpretations.

Exercise and restitution

For many of the participants, exercise *was perceived as* medicine, as they were motivated to exercise in the pursuit of recovery and/or cure from SCI or arthritis. These stories align with the dominant narrative of restitution that projects the hope of recovery following illness and injury (Frank, 2013). In this context, the participants were drawing upon the *exercise is restitution* narrative which specifically prescribes exercise as the means by which an ill or injured person can heal, and return to their former selves (Papathomas et al., 2015). Indeed, the word ‘medicine’ refers to both the treatment of illness and the art and science of healing (Malcom, in press). In understanding medicine as the latter, the EiM movement promotes and reinforces restitution as people ‘buy in’ to the perceived medicinal benefits of exercise:

I didn’t know anything about it, I still don’t know a great deal about it, but I actually thought arthritis was something that you could almost cure... I didn’t think that it was something that was going to be this debilitating. Right I see, people used to say “oh I have got a bit of arthritis”, and I used to think well you know “if they can do this with arthritis”, but I didn’t realise how bad it was going to get. So I just thought I was going to get better. So I thought the more activities I did the better, the better health I was going to get. [Jasmine, 65, OA, RA & Psoriatic Arthritis]

In this extract Jasmine recalled how the potential medicinal benefits to be gained from exercise *initially* motivated her engagement with these activities. This hope that exercise can lead to recovery following the onset of injury and illness is valuable in certain circumstances. For example, the desire for restitution to return to a life that mirrored the one lived before injury or illness can be a key motivator to start PA (Perrier et al., 2013; Papathomas et al., 2015), and

crucial for keeping people positive and engaged in rehabilitation (Soundy et al., 2013). Yet for others, exercise was perceived to be a route to cure:

I do this (ABR) Monday, Wednesday, Friday and then I try and do Tuesday, Thursday and Saturday down the gym. And then Tuesday and Thursday's I swim as well.

Interviewer: do you have any specific goals that you have in mind from exercise?

Get back to how I was. Yeah, get walking... I know I'm progressing, getting fitter on everything just as a whole... I haven't seen no massive improvement, no like all of a sudden my foot started moving, like being able to control my foot and stuff. I don't know, I've just heard a lot of stories of people in the chair and stuff and I think like 18 months or whatever, and getting stuff back. And funny enough there is one guy in the gym and he like took his first step after 3 years... I'll just keep going, trying you know.

[Daniel, 29, SCI]

With regard to narratives as actors that do things (Frank, 2010), the anticipation of restored function and cure from exercise *acted on* Daniel to motivate initial engagement in exercise and facilitated continued participation. As Daniel commented, he was getting fitter from partaking in his vigorous weekly exercise schedule. Yet his story also revealed the lack of movement and control of his body parts below his level of SCI despite exercising at this intensity. As taking action against SCI was the *source* of Daniel's hopefulness (Soundy et al., 2013), he was able to maintain hopes of recovery through exercise even when functional restoration was not forthcoming. The narrative environment within the gym (Gubrium & Holstein, 2009) further supported the exercise is restitution narrative for Daniel as stories of recovery were shared amongst others with SCI. In addition to the narrative environment, family and friends also helped sustain this storyline:

I don't think I should accept it, there is always hope. If there is one percent, there is a 99% chance I will never ever walk or do anything again but there's always that one percent chance someone's got to have it, why can't it be me? So, you never know and if you knew my life history and the things that have always happened and the things I've done... My mates say if there's any person that one day will get up and prove everyone wrong, it would be me. So, I've got to give it a chance, I want to walk in that boozier one day and go how about that, that was a poxy fucking 10 years but I'm back. [Nathan, 47, SCI]

As Nathan's story highlights, reflecting upon stories of the past with this friends helped shape a future of restitution. As Frank (2013) explains, the restitution story is the most culturally preferred narrative; anyone who is ill or injured wants to be healthy again. According, this preference for restoring health was reflected in participants' stories as they were co-constructed relationally with friends and family. For Nathan, like others, the stories of his past self – the life that he led before his injury – meant that he felt he could not 'accept' a future without the hope he will regain the life once lived before.

Although the exercise is restitution narrative can be beneficial in breeding determination and commitment to exercise, there may be some negative consequences in pursuing exercise for cure. In the first instance, although medication, surgery and exercise facilitate SCI and arthritis management; there remains no known cure for either condition (see Buchholz et al. 2009; Nelson et al. 2014). The hope of cure from these conditions can be perceived as counterproductive during rehabilitation as they can constrain a person's ability to narratively reconstruct their lives (Smith & Sparkes, 2005). The process of adaptation, adjustment and acceptance to accommodate a new body is considered essential in reconstructing life stories following injury or illness (Dibb

et al., 2013). In this context, acceptance is understood as an important psychological end point whereby people have accepted their current situation and have realistic hopes and expectations for the future (Soundy et al., 2010). For health professionals in SCI, the danger of unrealistic hopes and expectations of cure is the potential psychological distress and reduced well-being if recovery is not forthcoming in the long term (Williams et al., 2018). Therefore the exercise is restitution narrative can be a fragile form of motivation for those exercising as a cure for all ills (Papathomas et al., 2015).

Another concern with restitution is that it is increasingly becoming a commodity ‘that some can purchase and others cannot’ (Frank, 2013, p.95). The commodity argument translates well into the notion of exercise as restitution. For instance, many disabled people are motivated to exercise, yet face multiple barriers preventing them from doing so (Martin Ginis et al., 2016; Williams et al., 2014). These barriers experienced by people with arthritis and SCI align with a social relational understanding of disability (Richardson et al., 2017; Williams et al., 2017). In contrast to the medical model – where disability is ‘caused’ by impairment – the social relational model situates disability as a form of *social oppression* that arises from disabling and discriminatory conditions that impede activities such as exercise (Smith & Perrier, 2015; Thomas, 2012). Accordingly, health promotion has been criticised for perpetuating and reinforcing inequalities by ignoring sociocultural conditions impacting upon exercise participation (see Kay, 2016; Malcom, in press). Some of the participants’ stories echoed these inequalities and resonated with the social relational model of disability as they acknowledged difficulties in accessing exercise opportunities:

I think the concern for me... you don’t have loads of money as a PhD student, so that kind of limits a little bit of what I can do as well, because something like joining a nice

expensive gym that has spinning classes and, I don't know, some sort of personal trainer or something that can do adaptive sessions, or even joining something like a canoe club that I looked into, where you have to buy the canoe and all the equipment, at the moment I can't afford that... just frustrating that sometimes it is hard enough to force yourself to be active as it is, but when those options are limited it's even more difficult to motivate yourself. [Tammy, 26, OA]

As Tammy's comments illustrate, this lack of access to suitable and affordable exercise options was frustrating and de-motivating. In line with a social relational understanding of disability, this is one example of how the barriers experienced by disabled people can have a negative impact upon their psycho-emotional well-being (Richardson et al., 2017). In light of this, some participants were reticent of promoting exercise to their peers through fears these opportunities would be beyond their means:

You've got to be careful with, because it's just the funding. Someone could really want to come and someone could really want to do this, but if they ain't got no financial backing behind them it's not possible...

Interviewer: That would be your biggest worry, encouraging someone and then them not being able to afford it?

Yeah, I think I would have to, you'd have to know who you were talking. If they've had like a 5 million pound pay out then yeah, all for it. But you know, I wouldn't want to say to someone do it, and then you realise that they can't afford it. You know you've built their hopes up. It's hard, I don't know what I would do really if I couldn't afford it.

[Chris, 26, SCI]

Accordingly, health professionals, interventionists and policy makers need to be mindful of how the EiM initiative breeds restitution. When sold as a ‘miracle cure’ (AMRC, 2015), realistic expectations and experiences of exercise are not being managed. Moreover, if EiM is going to have any success in reducing inactivity in disabled populations, then the inequalities and oppression faced by disabled people need to be addressed. Through the EiM movement, exercise is touted as ‘a viable and relatively inexpensive way to combat most of the nation’s most serious diseases that are, for the most part, preventable’ (Berryman, 2010, p.200). Yet this is not the case for disabled people as exercise opportunities can be expensive, inaccessible, and require on going social support (Martin Ginis et al., 2016; Williams et al., 2017).

Exercise and pain

Commonly associated with the body being under harm or distress, the medical discourse understands pain as a symptom or indicator of other biological processes i.e. acute pain serves a purpose to protect us by signalling injury. Chronic pain however, which can persist in the face of diagnosis, treatment and even recovery, has no obvious biological purpose (Best, 2007). Pain is therefore an experience in need of interpretation; it is subjective, personal and informed by social and cultural contexts (Sparkes & Smith, 2008). The experience of pain will therefore vary according on the way it is socio-culturally constructed. For people with neurological and musculoskeletal conditions, pain can be a chronic, pathological symptom that limits daily living, including reduced physical activity and socialisation (Finnerup, 2013; Woolf, et al., 2012). To minimise the negative impact of chronic pain exercise is a widely recommended approach for both arthritis (Nelson et al., 2014; Pedersen & Saltin, 2015) and SCI (Jacobs & Nash, 2004; Norrbrink et al., 2012). In line with the EiM initiative, much literature suggests exercise presents medicinal qualities such as direct pain relief and reduced stiffness and fatigue (Bennell et al.,

2014; Cooney et al., 2011). Although some participants concurred with the idea that exercise helped manage pain – suggesting it was a useful “distractor” or a “loosener” – the majority also identified instances where exercise caused pain:

I just wanted to be a bit more supple, perhaps have a few less spasms as well and yeah just generally feel healthier. I found it (ABR) was no better than anything else I was doing before... And I don't feel better for it necessarily. Because I do a lot of pushing and it pains in my elbow, my joints and stuff like that. [Steve, 37, SCI]

Steve’s experience outlines a fundamental issue that personal experience may not fit the simplistic and idealized exercise-health relationship projected by dominant EiM discourses. When exercise causes pain and fails to yield health benefits there is a danger that long-term motivation may be thwarted when exercise does not fulfill expectations. Likewise, exercise was also described as leading to harm:

I tried exercising and the doctor gave me a referral to the gym and I tried doing that and what happened was I blacked out on the treadmill and hurt my body so that put me off, it was just a lot. Because they do say you know “exercise will do you good” and you know take the weight off the joints, but if you are unable to, if you are less mobile how are you going to do it? [Liz, 51, RA]

Liz’s story is representative of the overarching goal of EiM in that she was prescribed exercise by a medical professional (Sallis, 2015). Yet for her, the consequences are not symptom amelioration but rather symptom aggravation. Further pain and hurt is at odds with her perceived messages about the role of exercise; ‘they do say, you know, exercise will do you good’. The EiM movement’s amnesia regarding possible side-effects (Nesti, 2016; Malcolm, in press) filters down to everyday practices and this may, as implied in Liz and Steve’s story, lead individual’s to

overvalue its benefits and underestimate its consequences. The risk is that without providing the full story of EiM, potential benefactors are shocked and ‘put off’. Liz went on to identify a fundamental flaw with EiM when she stated ‘if you are less mobile how are you going to do it?’ Essentially, the efficacy of EiM is futile if your impairment precludes you from engaging with it. Scholars have asserted that the realities of life may besiege any medicinal benefits exercise may have (Beedie et al., 2016). The dangers of a blanket promotion of EiM were also alluded to in the data:

A bit of swimming, but having the psoriasis, chlorine aggravates it, so they say swim, it is really good for you. Well yeah, but I want to itch when I come out the pool and if you are covered in a rash afterwards... I suppose it became easier to have an excuse not to exercise. It hurts or it brings me out in a rash, and then it sort of went the other way from loving exercise to not wanting to do it. I think that has been my problem ever since.

[Jessica, 50, Psoriatic Arthritis]

One of the principal criticisms of the EiM initiative is that it prescribes exercise to entire populations with a disregard for condition-specific symptoms (Malcom, in press). From Jessica’s perspective, when exercise does not deliver the medicinal effect that was promised, her enjoyment and motivation for activity diminish. By overemphasising the benefits of exercise and neglecting to make patients aware of side effects it does not prepare patients for potential negative impacts. To counter this, EiM must tell a more authentic tale that incorporates good, bad and indifferent exercise experiences and duly manages the expectations of its potential benefactors. Recent research has suggested that when exercise is prescribed to patients they want to be better supported, particularly during the early stages of engagement (Joelsson et al., 2017).

To achieve this, medical professionals must listen to the patient and take into account their individual circumstances, context, and symptoms.

Sensitizing to person-specific factors in this way resonates with Charon's (2006) notion of narrative medicine; incorporating a patient's illness story into medical decision-making. Although narrative medicine is a growing feature of medical education (Gray, 2009), not all health professionals are willing or able to elicit, absorb and interpret illness stories (Johna & Rahman, 2011). Even when health professionals possess such narrative competence, time constrained consultations (see Flaxman, 2015) and efforts to technologically automate medical encounters (see Ng et al., 2016) may limit the opportunity for narratives to be heard. In terms of exercise promotion in clinical populations, not tending to personal stories might result in physical activity recommendations that are too general. For many of the participants in this study, exercise advice was simplistic, and lacked nuance and directional support. As Jessica reflected, this didactic approach had the potential to go awry:

I have got my watch which records my step so I try to do six thousand steps a day which is the recommended amount by the arthritis association. I will do more, and I can do more, but then the following day I can't move. I just seize up because I have done so much. I mean I walked round London one day ... I did something like 27000 steps. I was enjoying it, it was a lovely day and I was getting quite stiff but I thought if I stop then I won't get up again. So I just kept moving. The following morning I couldn't even get out of bed [Jessica, 50, Psoriatic Arthritis]

Jessica's story depicts exercise as an enjoyable experience but also one that can cause pain and debilitation. Although Jessica received generic guidelines for activity levels, the broader EiM initiative promotes that more exercise is always good and gives the patient control over how

much to do (Malcom, in press). That is, cultural notions of healthism, such as the patient taking responsibility for their activity, may mean that specific guidelines are overridden by the individual. Guarding against extreme responses to exercise promotion (too much or too little) is an important but seldom used practical strategy (Ladwig et al., 2017). For individuals with arthritis, regularly overdoing exercise can be a barrier to future involvement, as exercise becomes associated with more pain than the condition itself (Petursdottir et al., 2010). Of course, the notion of “overdoing it” will vary for different people.

A common critique of physical activity guidelines is that they lack individual specificity (Iversen et al., 2012; van Dillen et al., 2013) and this may be especially problematic in clinical populations where symptom severity can vary greatly. Guidance must be tailored to each injury or illness, the particular health benefits sought and the personal characteristics of the exerciser; a difficult, if not impossible, task within a generic set of guidelines. The problem is further compounded by little consensus on the dose-response relationship between exercise and health (Samitz et al., 2011). Lastly, the burgeoning use of technology as a health surveillance tool may undermine exercise recommendations for clinical populations. Physical activity monitoring devices such as that used by Jessica, can deliver activity prompts, set goals and reward achievements; all of which work to encourage a person to do more (Lupton, 2013). This unsophisticated message of “the more the better” is not always applicable to the circumstances of clinical illness.

Beyond debates about guidelines and dose-response, the uncritical promotion of exercise risks overlooking situations where a prescribed activity is not physically possible or medically appropriate:

It (exercise) caused pain, and if it causes pain you think it's making it flare and oh my god I'm going to be really ill ... you automatically presume that you get pain and that's it, the arthritis is flaring, you are going to be ill, you won't be able to do anything at all, therefore stop, and hopefully it will go away. You are always told to rest if you get a flare but you can take it too far and I think I did take it way too far and then it becomes a habit and then once you are in the habit it is very difficult to break. Then you get miserable and depressed so you become more entrenched in your habit and so on. [Jessica, 50, Psoriatic Arthritis]

Jessica described how she felt "miserable and depressed" when she became inactive due to her condition. Physical inactivity is conceived of as a difficult to break bad habit that breeds negative emotions. Smith and Perrier (2015) further discuss this idea, suggesting that by putting responsibility onto individuals to be active for their health we promote social labels whereby those who are active are "good" citizens and those who are inactive are "bad". Health promotion efforts like EiM must guard against an overemphasis on personal responsibility as it may lead to feelings of guilt when a given behaviour cannot be realised due to medical complications (Guttman & Ressler, 2001). Additionally, being active itself may lead to feelings of stress and worry, as well as causing physical harm:

That's what worries me crashing down and hitting my head you know... yeah sometimes I just don't want to go out in case something like that happens ... I don't enjoy myself going out sometimes because you are wary of what you will trip over or if I was there and something gives way and you, you just, your hips go and go away from you and you are gone. [Graham, 57, OA]

For Graham, the prospect of physical activity created fear and worry that he will become injured and as a result be put in serious harm. This problematizes the notion of exercising for mental health benefits, as studies show that fear of pain is associated with increased psychological distress (Goesling et al., 2013). Further, fear of pain/experiencing a flare-up is a common barrier to exercise for people with arthritis (Gyurcsik et al., 2009; Wilcox et al., 2006). For individuals with clinical conditions such as arthritis and SCI, the potential for exercise-related pain may lead to anxiety and act as a barrier to engagement. Exercise promotion efforts may wish to consider prescribing according to what is feasible rather than what is best for physiological health.

Exercise and pleasure

Across disciplinary divides, there is consensus that the feeling of pleasure is experienced through diverse emotions – such as happiness, fun, joy, sensuality, satisfaction – that make a person feel good (Phoenix & Orr, 2015). Situated with a broader understanding of affect, there is a growing body of literature exploring the association between exercise and pleasure. For example, within exercise psychology, affective valence (pleasure and displeasure) and distinctive affective states (emotion and mood), have been identified as a key component of the exercise experience (Ekkekakis et al., 2011; Rhodes & Kates, 2015). In line with this literature, and in contrast to pain, many of the participants' stories revealed the pleasures and positive emotions to be gained from exercise:

There are other benefits other than the increased mobility in exercise, there is the feeling of well-being those little endorphins get kicking in and you go... the last thing you want to do is get up and be down in a gym to meet up with a trainer at half 8 on a Monday morning. Who wants to do that? But if it's a sunny morning, you go out, you are outside

doing some stretching and stuff like that, you just feel good for the rest of the day, it's just lovely, and even if you are a little bit stiff afterwards then the benefit is from the feeling good factor inside. [Isabelle, 62, OA]

As Isabelle described, the positive affective experience of 'feeling good' from exercise helped sustain her continued participation and overrides any negative affective responses such as stiffness. Yet moving beyond understandings of emotions as psychological states that reside within the individual, our analysis also identified the multiple ways exercise was perceived as pleasurable through a relational understanding of affect (see Fullagar & Pavlidis, 2017; Tamminen & Bennett, 2017). Drawing upon sociocultural frameworks, affect, feelings and emotions are positioned as social, intersubjective and embodied (Tamminen & Bennett, 2017). In other words, emotions do not emerge from the mind but are produced relationally between objects and bodies as there is always somebody or something to whom these feelings are related (Fullagar & Pavlidis, 2017). For example, many of our participants commented upon the embodied sensory dimension of pleasure:

To start off with, after each session I feel good, just makes you feel good. You're tired but it's just like, literally like you've been for a run, there's nothing else, it's very, very hard for me to get that feeling now. That feel good just after you finish is a massive part of it... The way it makes you feel, that tiredness, that out of breath feeling, that's not something you get all the time after this happens to you. I love it, I really enjoy it, I find it really addictive. [Stuart, 20, SCI]

Sensual pleasure can be defined by the senses, mainly touch and feel, connecting people to the experience of pleasure during exercise (Phoenix & Orr, 2014). Following SCI and subsequent paralysis, assisted exercise rehabilitation was the only vehicle that replicated the

embodied feelings and sensual pleasure of an intense physical workout. Likewise, Nathan's comments echoed those of Stuart as he recounted the pleasure of being physically handled by his personal trainers:

I quite like the idea of being put on the bench and being manhandled really. Pulled about arms legs and everything... I come away like sitting down my arms are aching, I ache.

It's a nice feeling just to be aching, just to feel like you are aching because your arms and stuff that you thought wouldn't hurt. Even my stomach, I can feel my stomach muscles pounding away a little bit which I really shouldn't be but it's great. [Nathan, 47, SCI]

Nathan's comment indicates the intimate connection between his sensual body and the surrounding environment (Coveney & Bunton, 2003; Phoenix & Orr, 2014). In this instance, the surrounding environment included the physicality of the exercise machines and interaction with other bodies including the trainers and assistants. Thus, emotions are embodied in that they are felt within the body, yet they also intersubjective as they arise out of relationships with others (Burkitt, 2014). Nathan, like many other clients, also referred to the pleasure of sensing 'that aching feeling' after exercise in areas of his body where he otherwise has no sensation. As well as experiencing sensual pleasure as instant gratification, Nathan implied that the aching lasts beyond the duration of his exercise session. This is an example of how pleasure is bounded by the time, place and space in which the exercise took place (Gerdin & Pringle, 2017), and how the feeling of pleasure can *expand* into the immediate aftermath of the activity (Phoenix & Orr, 2014).

Another type of pleasure that was identified specifically in stories of participants with SCI was the *pleasure of 'normative' activity*. In this instance 'normative' activities referred to standing, walking and cycling, many of which the participants could no longer carry out

independently post-injury. Exercise programmes that involve aspects of walking have been identified as representative of both normative and desirable activities for people with SCI (Jordan et al., 2013). Furthermore, in line with restitution, engaging in exercise programmes are associated with a momentary return to one's past self (Frank, 2013). George's comments, echoing many of the other participants, suggested that through the pleasure of 'normative' activity, he was able to connect to his former 'able' body:

I really enjoy the walking aspect of it. I don't know why, I don't know if it's because you are up straight and walking. I don't get tired, it's hard work but because you enjoy it I think you do it more. And the spin bike as well because I'm able to do that on my own without any helpers. I think with the spin bike and the walking it's like a normal thing you would do day-to-day. I don't get to do walking at all at home, so when I'm up here and I get half hour, 45 minutes of walking it's like a natural thing, a more real thing and it brings you back to what it was like before. [George, 22, SCI]

In addition to pleasure from normative activities, participants experienced pleasure from immersing themselves within their exercise environment. As Phoenix & Orr (2014) explain, pleasure is experienced from the focus and immersion in an activity that allows people to escape from everyday issues in their lives. For new materialist scholars, *pleasure through immersion* is an example of the complex *relations of affect* that act upon individuals to alleviate (or produce) experiences of distress (see Fullagar, in press). Extending the understanding of exercise as a distraction (Ekkekakis et al., 2013), through the process of *detachment* from everyday issues, pleasure through immersion can also be achieved relationally through *attachment* to another place (Phoenix & Orr, 2014). In this context, some participants were able to experience pleasure through immersion as exercising redirected their focus away from the daily struggles of life.

Matthew exemplified this as he described the pleasure he experienced from regularly spending his weekdays in an enabling, accessible and supportive environment:

You get a better vibe when you come in here, I go home on a weekend every weekend and I can't wait to come back on Monday. Everyone gets on well, you can have a laugh and a joke with the physios and like I said the music is on. It feels like a proper gym, but it's just you need that little bit of assistance and some of the stuff you are doing you wouldn't see on a regular gym... it doesn't feel like a chore to come here it feels like you want to come because of the enjoyment you get out of it, as much as what benefits you get out of it as well [Matthew, 22, SCI]

As with sensual pleasure and the pleasure of normative activity, the pleasure of immersion was most intense *during* the activity of exercising. That said, as Matthew's comment suggests, the pleasure of immersion has the potential to extend *beyond* his exercise sessions as the excitement built over the weekend. While affect experienced during activity has been identified as the strongest predictor of future exercise engagement and motivation (Rhodes & Kate, 2015), our results illuminate the various ways pleasure experienced beyond the activity can motivate people to remain physically active. For example, another type of pleasure experienced *after* the moment of doing activity was documented pleasure. *Documented pleasure* occurs through the process and outcome of documenting one's activities (through manuals and diaries etc.) which becomes a pleasurable act (Coveney & Bunton, 2003; Phoenix & Orr, 2014). In some instances, participants' stories included aspects of documented pleasure as they discussed their physical progress by monitoring improvements in strength and fitness through their rigorous training.

The last type of pleasure identified in the participants' stories was expressed as a form of *habitual pleasure*. This refers to the routine of regular exercise that provides a sense of structure to peoples' lives. As Phoenix & Orr (2014) note, the pleasure gained from habitual action is especially important in the aftermath of life changing events where people can find the expanse of un-allocated time overwhelming. The routinized behaviour of regularly exercising provided our participants with a sense of constructive use of their expansive free time:

Yeah just like you know, you feel happier and when I leave here my endorphin levels are crazy, I'm on a high. During the week I feel better as well like, and knowing that, because I wasn't really doing anything constructive as well with my time. So this is like a good two-hour constructive thing that I'm doing every week, that's fixed as I'm not working or anything at the moment I was so just wasting time watching TV and everything. So I find this something useful I'm doing. [Lee, 26, SCI]

These different types of pleasure to be gained from exercise illuminate the narrow rigidity of the EiM movement to capture the experiences of those who want to exercise simply for pleasure. As Malcom (in press) notes, the EiM movement may de-emphasize important emotional drives for exercise – such as fun, joy and excitement – with goals of health and evaluation of health outcomes. Thus, much of the research in health promotion is underpinned by cognitive theories of behaviour change depicting humans as rational decision makers and ignoring the role of affect and emotion in predicting exercise intentions and actions (Ekkekakis & Dafermos, 2012). Indeed, exercise behaviour change interventions specifically designed to engage people with SCI and arthritis rarely include pleasure and enjoyment (Williams et al., 2017), despite its integral role in exercise maintenance and its capacity to *contribute* to health in its own right (Phoenix and Orr, 2014).

Accordingly, framing exercise as a “health behaviour” rather than say a “leisure pursuit” can change the way exercise is experienced, e.g., tiring and laborious rather than energising and fun (Werle et al., 2015). To this end, well-intentioned EiM messaging along the lines of “exercise for health...and it’s fun” (see Public Health England, 2014) must reflect upon the possibility that the former may suppress the later. In clinical populations, these concerns are exaggerated as the overt focus on condition-specific health benefits ‘medicalises’ exercise for disabled people and ignores other possible exercise experiences. While mindful that exercise cannot be pleasurable for all, health professionals, policy makers and interventionists require the knowledge and practical resources to communicate, educate and foster affective possibilities in new and/or forgotten embodied pleasures of exercise (Fullagar, in press; Phoenix & Orr, 2015). Moreover, prescribing exercise around affect – exercise that will be enjoyable – should supersede prescriptions based on physiological health (Ladwig et al., 2017). The rationale underpinning this assertion is that exercise must be enjoyable if it is to be sustained long-term, a hypothesis that holds particular relevance for clinical populations who can experience pain when exercising.

Conclusion

Drawing on data from two clinical populations, we have applied a critical lens to the EiM movement. It is important to scrutinize the broad discourse of EiM as grand narratives like this can run unchecked (Andrews, 2002), despite their power to shape cultural, institutional and personal practices (Schmidt, 2008; Somers, 1994). We have duly highlighted numerous limitations to the notion of EiM, most of which are underpinned by an overly simplistic depiction of exercise as a cure for all ills. The absence of nuance within the broad EiM discourse is at odds with the world it so desperately wants to inhabit. Specifically, as pharmaceutical medicine and

clinical healthcare moves steadfastly towards a model of personalised medicine (Hays, 2017); EiM continues to trump exercise for everyone and everything. Where medical science has begun to acknowledge the vast interpatient heterogeneity within conditions and the importance of matching patients with treatment (Isaacs & Ferraccioli, 2011); EiM has failed to move beyond whole population guidelines and struggles to specify dosage beyond a basic message of “some-good more-better”. The one-size fits all mantra is outdated. Our goal in taking this critical perspective is not to undermine the value of the EiM movement but rather to consider its flaws and how these might be addressed for the good of health promotion efforts.

Given the data in this study and our associated critical analysis, we argue that the promotion of exercise for medicinal purposes must be an ethically-informed decision. The diversity of exercise experiences described by participants with SCI and arthritis suggest that those prescribing exercise to clinical populations need to think carefully about the rationale for doing so and the broad impact it may have. The current ACSM homepage for the EiM initiative affords no space to ethical considerations or ethical guidelines relating to exercise prescription. Yet, if exercise is medicine, and if it has a role to play in the treatment and management of chronic ill health, its use must be held to the same ethical standards as traditional medical practices. Similarly, other than an isolated number of sociological commentaries (e.g., Fullagar, in press; Malcolm, in press; Nesti, 2016; Neville, 2013), few academics working within the broad realm of exercise for health benefits have engaged in ethical debates around the principles and practice of EiM. Contrast this with chemotherapy treatment where there is an abundance of literature regarding its ethical use according to various contexts (e.g., Manos et al., 2015; McLennon et al., 2013). This is an important future direction for EiM advocates; what does an ethical EiM look like?

The most dominant model of ethics within mainstream medical practice is Beauchamp and Childress' (2001) 4 pillars of biomedical ethics. The four pillars can be briefly articulated as: a) respect for autonomy – patient's wishes and values, b) non-maleficence – avoid harm, c) beneficence – bring about benefits and d) justice – equality of practice. Applying this ethical framework to our own data it becomes apparent that prescribing exercise may not always be an ethical practice. The complex relationship between chronic illness and injury with exercise dictates that although an ethical pillar is fulfilled in one time and context, it may not be fulfilled in another. For example, non-maleficence can quickly become maleficence as in the case of SCI individuals who become frustrated when exercise does not bring the recovery hoped for. Autonomy is another problem area for EiM because of its emphasis on exercise as a health obligation; it is less of a choice and more of a personal and social responsibility (Neville, 2013). Similarly, in terms of justice, there are grave inequalities related to exercise opportunities (Kay, 2016; Williams, 2017) and our own data highlights the commodity element to exercise. These are real concerns that must be debated if the great "beneficence" of exercise is to be realised. We have drawn upon the 4 pillars model for its dominance in medicine but other ethical models exist. For example, a relational ethical approach recognises the need to study ethical issues from the perspective of the individual (Sparkes & Smith, 2014). Through this stance, exercise promoters need to use the socially constructed worlds of the chronically ill and injured as the starting point for their efforts rather than appeal to the broad, person-insensitive logic of the EiM movement.

In conclusion, exercise is mostly good and good for most; but not always and not for all. Letting go of dogma in favour of more nuanced, reflective, and ethically scrutinised forms of exercise promotion may lead to more efficacious, person-sensitive interventions. Awareness of

individual circumstances, passions and priorities can help tailor exercise promotion and prescription so that it does not breed feelings of guilt and self-blame when adherence proves difficult or impossible. Dosage cannot simply be a function of physical benefit but must also incorporate psychosocial circumstance and condition-specific impairment. Further, fully considering the pros and cons is more likely to engender a robust commitment to exercise than naively accepting a romanticised depiction that leads to unexpected disappointment. There is no room for blind advocacy in the complex world of chronic illness and injury, where pain and disability can interrupt the EiM rally cry. If exercise is indeed medicine, there is a case for academics, interventionists and health professionals to reflect on how we might begin to promote and prescribe it in an ethical way.

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