The pain self-management paradox:

Why do we focus on the individual when life-context plays such a major role?

Background

This article is a much-condensed version of my book about the self-management of persistent pain¹. I am concerned that we have come to rely on self-management as an approach to pain management whilst at the same time it feels like we are somehow losing focus on the people who live with pain and, more importantly, the context in which they live with their pain. We seem to have forgotten that although self-management is absolutely vital in the process of living well with pain, it is not the only element which is important.

At this point, it is important to make very clear that I am not suggesting that self-management is unimportant. There are many people working extremely hard to raise awareness of self-management and to make self-management accessible. On the contrary, I see self-management as vital. But, I see self-management as one part of the pain management puzzle. I feel we should be more mindful of a person's life context (their financial and social capital, the environment in which they live, the economy, the policies imposed by government, the language used when we talk about self-management, the facilities they can or can't access, the ongoing support they can or cannot count on). I'd like to find a different term, one that does not place all the focus on the 'self' (the person who lives with pain).

Approaches to pain self-management focus on one person: the person who lives with persistent pain. People who live with pain are taught coping skills, or perhaps they learn through Acceptance and Commitment Therapy (ACT) to reach a level of acceptance that enables them to engage with valued activities, despite their pain, or maybe they learn through Cognitive Behavioural Therapy (CBT) to better understand the relationships between their thoughts emotions and behaviours². These approaches are important and there is much literature to support them. I am not quibbling with this evidence. I see the value in these approaches. However, all these approaches focus on the person with persistent pain and I think we could do better at remembering that that person does not live in a vacuum. They live somewhere. Maybe they live somewhere deprived, maybe they live somewhere affluent. Maybe they have good social support. Maybe they have limited, or no social support. Maybe

they live in an inner city tower block where the lift is often out of order. Maybe they live in a rural area where there is no reliable public transport. Maybe they have high or low health literacy. All of these things (and others) will impact on that person's ability to self-manage.

I believe that a refocusing is required so that we can take a wider view of how we approach pain self-management. I'd like us to find a different term, one that does not incorporate the word 'self' and the connotations that are tied to that word. I'd like us to continue to encourage individuals to play an active role in coping with their pain, but I would also like us to shift to seeing self-management *as part of a* wider approach to living well with persistent pain that takes into account individual's life contexts.

Defining and measuring self-management

Our health system was developed to deal with acute episodic care not the ongoing supervision, observation and care needed by those living with chronic conditions³. Yet the numbers of those living with chronic conditions and therefore needing ongoing health care is increasing. And as the numbers needing long term care and support increase, so too does the cost to the NHS. Indeed, in 2016, Fayaz and colleagues⁴ wrote a paper on the prevalence of persistent pain in the UK. In their introduction they mention that persistent pain has been "highlighted as one of the most prominent causes of disability worldwide". In 2008 it was estimated that up to 8 million people in the UK lived with persistent pain⁵ and just eight years later⁴, it was suggested that this was a considerable underestimate. They suggested that there were in fact 28 million people in the UK living with persistent pain; this equated to 43.5% of the UK population. Furthermore, when they looked at the data by age, this percentage rose to 62% for those over the age of seventy-five.

So, we know that persistent pain affects a large proportion of the general population, and that as our population ages, the numbers of people affected will increase. These people are often described as using a disproportionately high level of health and social care services⁶. Add to this the years of decreasing investment in our health system and it is not so surprising that the search for a solution has led to the idea that people with long-term conditions should play a more active role in managing their conditions^{7,8}. For example, the definition proposed by Adams et al.⁹ states self-management involves "having the confidence to deal with medical"

management, role management and emotional management of their conditions." Whilst others¹⁰ note that "at a broad level, self-management is defined as the day-to-day management of chronic conditions by individuals over the course of an illness."

Self-management typically involves a multitude of actions: managing the condition, engaging in healthy lifestyle behaviours, adjusting to illness enforced changes in social, vocational, economic roles, making conscious health-related decisions, learning and becoming informed about the condition, forming a good relationship with the health care providers. As such the umbrella term self-management is complex, difficult conceptualise and define. What counts as successful self-management, day-to-day management, a good relationship with health care providers is open to interpretation. For example, does the health professional and the person living with pain have the same interpretation? The more you read around the subject, the more apparent it becomes that there is currently no clear consensus about what is meant by self-management. This is encapsulated in the quote¹⁰ where it is noted that the term self-management "is described by a variety of definitions and conceptualisations, which contribute to a lack of clarity and agreement in the literature".

A consequence of this lack of definitional agreement is that we do not yet have an accurate measure of self-management. Since there are many definitions, it is not surprising that there are many measures. For example, Banerjee and colleagues¹¹ published the results of their review of outcome measures that were designed to assess self-management in patients with chronic pain. Their aim was to identify, appraise and synthesise the range of outcome measures so that they could provide definitive information that would help researchers and clinicians choose the most appropriate tool to assess self-management. In contrast, Packer and colleagues¹² focused on two things; the first to identify the self-report scales that were being used to measure self-management of adults with chronic conditions, and the second to describe the intended purpose, theoretical foundation, scope and dimensionality of the scales.

Both sets of researchers reported that not only were many measures being used, each measure focused on a different aspect of the difficult-to-define-term 'self-management'.

Banerjee and colleagues¹¹ identified 14 scales that were being used as a proxy measure to

assess self-management whilst Packer and colleagues¹² identified 28 self-management scales. These included measures of self-efficacy, quality of life, psychological well-being, physical functioning, condition-related knowledge, helplessness, emotional support, social support, and so on. In short, since the definition of self-management is diverse, the number of questionnaires purporting either to measure self-management or to act as a proxy measure of self-management is large.

To date, no scale measures self-management in its full multi-dimensional glory. This in turn means that without agreed definitions and measures, we cannot fully establish the effectiveness of self-management¹³. Indeed, Packer and colleagues¹² conclude that self-management is a "complex, multidimensional construct, and that existing measures assess different but related aspects of self-management". How then do we know what successful self-management looks like? If there are no clear definitions, then how do we know that when we use the term 'self-management', we mean the same thing as someone else using the same term? How do we know if health professionals and people living with persistent pain have the same understanding of self-management?

Implementing self-management: what is the problem?

Even though the concept of self-management lacks an agreed definition as well as ways of measuring and evaluating it, there is broad agreement on the content of persistent pain self-management programmes. Typically the focus of persistent pain self-management encourages individuals to learn how to manage their pain through maintaining their treatment regimen, pacing their activities and learning to control the physical, emotional and social consequences of their condition¹⁴. So self-management involves a multitude of actions: managing the condition, engaging in healthy lifestyle behaviours, adjusting to illness enforced changes in our social, vocational, economic roles, making conscious decisions, learning and becoming informed about the condition, forming a good relationship with the health care providers.

These activities require the individual who lives with persistent pain to play a proactive role. However, their ability to do so is not necessarily entirely under their own control. We don't live in a vacuum. After all, we are affected by the wider society in which we live, by the

systemic, political, economic circumstances of our society. We are affected by our own financial and social capital, or lack thereof. Yet consistently the self-management definitions focus on the individual whilst ignoring the wider life context. For example, Bringsvor and colleagues¹⁵ identified eight domains, all focused on the individual, which include positive and active engagement in life; health directed activities; skill and technique acquisition; constructive attitudes and approaches and health services navigation. Similarly, Nøst and colleagues¹⁶ suggest that self-management skills were related to "problem-solving, decision-making, resource utilisation, forming a patient-healthcare provider relationship, and taking action". Padilha and colleagues¹⁷ note that self-management is itself a dynamic process focusing on the "patient's capacity to self-control the symptoms, the treatment regimen and the physical, emotional and social consequences of the disease". The emphasis is on the patient to make behavioural changes to their daily living habits, to learn to self-monitor their conditions and to ensure they 'implement' cognitive, behavioural and emotional responses needed to control the progression of the disease and of their autonomy and quality of life.

Indeed, the phrase 'self-management' emphasises the self, the individual, the person living with the health condition. In so doing, this places all the responsibility for successful self-management onto the person living with persistent pain. It ignores the context or the background of the person's life, their support network (or lack thereof), their health literacy (or lack thereof), their financial capacity (or lack thereof), their social capital (or lack thereof) and their relationship with their health professionals (or lack thereof). And yet, the person living with pain is expected to cope. It seems to me that we are expecting a lot from our patients who are learning to cope with their condition, the ramifications of their condition and its impact on all aspects of their life.

In my professional world of health psychology, we have a model that has been successfully employed to better understand the range of barriers and facilitators to behaviour change. This model is known as the COM-B^{18,19}. COM-B is also an acronym which stands for the key elements of the model: 'Capability', 'Opportunity', Motivation' and 'Behaviour'. Without capability, opportunity and motivation it is argued that behaviour change will not be successful. The COM-B model clearly shows that a focus on the individual alone will not result in successful behaviour change. An individual may be capable (informed and have the skills)

and motivated, but if they do not have the opportunity then behaviour change will not be successful. Opportunity is defined as all the factors that lie outside the individual that make the behaviour possible or prompt it. In other words, 'opportunity' is equivalent to a person's life context. The potential relevance of the COM-B as a framework for viewing self-management training is therefore useful because it ensures that life context is taken into account when thinking about behaviour change.

So where does 'life-context' fit?

In self-management as commonly 'done', the patient is expected to take responsibility for their condition. Fonte and colleagues²⁰ argue that although the process of assuming responsibility is a key self-management skill, the literature has tended to ignore the psychosocial processes that are involved with taking on this responsibility. In their paper, they frame the process of taking responsibility as presenting oneself as an adult. However, in the health context we traditionally expect our patients to show deference to and seek approval from, health professionals. It is difficult to act as an adult, when we are expected to obey our health professionals. For example, there is plenty of evidence in the research literature to show how expert patients have been undermined by the health profession. In the diabetes field^{21,22} patients were educated and gained the competence and confidence to manage their diabetes. Patients who successfully completed the training were provided with a formal letter detailing the training and their expertise and competence, yet time and again health professionals overrode and undermined these patients. So even when patients have completed training (which had been approved and recommended by the UK National Institute for Health and Clinical Excellence (NICE)), health professionals more used to holding the expert role scuppered the patient's ability to act as an adult.

Of course it is reasonable to expect people to take some responsibility, but managing, coping with, and more importantly living well with a persistent pain condition is not something that can be done alone. Done well, it is a joint effort, involving collaboration with for example, loved ones, the health profession, the social system and employers. If we only focus on the individual, the 'self', then we ignore the complexity of the problem. When we do that, we give space for individual patients to be blamed when they fail to 'self-manage'. See for example research in the cardiac field reported by Granger and colleagues²³ who explored the way in

which communication about how to self-manage after heart failure was experienced and understood by both patients and their physicians. They reported that patients used terms like 'hard work' when describing what was expected of them. In contrast, physicians felt that their instructions were 'easy' and when patients struggled to implement them, it must be because they had not properly engaged. Patients said it was hard to manage without help, whilst physicians felt that patients did not properly understand their 'easy' instructions and assumed that they simply needed to repeat their instructions. Similarly, a body of work by De Ruddere and colleagues²⁴⁻²⁷ showed how perception of patients by health professionals can influence treatment. For example how likeable a person living with pain was perceived to be was shown to influence how seriously their pain was taken. Those who were not liked had their pain estimated to be less intense than those who were liked²⁴. In other words, health professionals were not hearing their patients and because of this they were not understanding the way in which their patients' life contexts impacted on their patients' ability to cope. which leads me to my next point. We as health professionals need to become more comfortable about seeing our role as a collaborator.

How can we as health professionals offer advice, recommendations or instructions unless we have some understanding of the context in which our patients live? In the same way that we know behaviour change is not straightforward (often even when we know something is not so good for us, (think of the decision to have dessert at the end of a meal when we are already full up), we may do it anyway, whether consciously or habitually), why then do proponents of self-management assume that instructions are given and people will implement them? And why are we quick to describe someone as 'not engaging' when they struggle to self-manage? Unless we refocus the way we 'do; self-management, when people living with pain do not implement or incorporate self-management into their daily lives, they will likely find themselves judged and blamed and described as non-compliant, disengaged, or difficult.

What might refocusing self-management look like?

I am by no means the first to voice these concerns; Entwistle and colleagues¹⁴ as well as Coulter and colleagues²⁸ amongst others have questioned whether self-management as it currently operates has too narrow a focus on *managing* the condition, rather than on *living* well with the condition. So what would a refocus look like? Could we move away from self-

management with its nominative deterministic focus on the individual, towards something new? Could we move towards 'collaborment'?

Collaborment¹ combines collaboration and management. A term that has at its core a recognition that an individual cannot possibly manage in a vacuum. A recognition that the patient's life context impacts on their ability to do (or not do) things. A recognition that the person living with the condition has a level of expertise that should be recognised. A recognition that the patient has a nuanced knowledge and understanding of what will work for them in their life context. A recognition that the person living with the condition could be empowered to make informed decisions about how they live their life and manage their condition.

But we also know that it can be hard for health professionals to accept and acknowledge patients as experts. If at this point we refer back to the diabetes work of Snow and colleagues²², they noted that often patients who had completed an intensive patient diabetes education programme had "specific biomedical, experiential and practical knowledge that exceeds that of many health professionals." This expertise should have been valued but instead the response of health professionals in effect prevented patients from implementing their training. Similarly, Francis and colleagues¹³ found that patients generally understood the information and advice they received and worked hard to meet the goals set. However the lack of structural resources often prevented them from following through on their commitments (i.e. lack of opportunity thwarted them). In the same study, health professionals considered patients to have innate capacity for personal agency which would overcome barriers. However at the same time, it was clear that if a patient employed their personal agency to reach a decision about what they felt was best for them, this was only seen as positive if the patient's decision corresponded with the physician's advice. Personal agency is only a 'good thing' when it matches the opinions of the health professional.

This mismatch in perceptions was explored by Slightam and colleagues²⁹ who noted that health professionals tended to focus on providing guideline-concordant care whereas

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¹After I coined the term I did a Google search and found collaborment as a term exists in the context of cooperative inline gaming http://neoheurism.blogspot.com/

patients focused on the aspects of their condition(s) that they found most burdensome or uncomfortable. In other words, patients focused on the aspect of their condition(s) that had the most impact on their ability to do the things they wanted. The researchers concluded that health professionals should take the time to find out from the patient what it is like to live with the multiple conditions, to understand the daily burden imposed by the condition(s) and in turn to better understand how this impacts on the priorities of the patient. Quite simply, if a health professional can focus on the aspect of a condition that is causing the patient discomfort, or burden, even if it is not the aspect we would have chosen to focus on first, we may find we have removed a barrier to that person being able to manage better. Are we as health professionals really trying to understand things from the patient's perspective? Are we listening *properly?* Are we *hearing* what the patient is saying and do we understand the context in which the patient is living? If not, how can health professionals and patients ever agree on successful outcomes? How can we move to a focus on living well?

Future Perspectives

There are things we can do as health professionals. We could be more open to exploring what living well means to the person who has persistent pain. We could recognise that living well will be different for each person and may be different from our own definition. Indeed, collaborment is all about working with the patient and with other health professionals. It is about being prepared to listen to the patient and take seriously their priorities, their wishes, and their expertise. At this point it is important to highlight that a checklist of solutions cannot be included, for they will be dependent on the life context of the person in pain and that of the health professional(s) working with them. The intention behind this think piece was to raise awareness of the other parts of the puzzle that can impact on how we manage pain collaboratively.

Looking ahead might the notion of collaboration be built into training programmes for all health professionals? Such a shift in perspective would go some way towards helping trainees recognise that they can't possibly know everything and more importantly that it is OK to work with, and learn from, their patients. Can we lobby the overseers of education, those who accredit courses for our health professionals? Can we ensure pain is a core part of the training? For example, Biggs and colleagues³⁰ noted that pain education was a marginal topic

and considered a non-essential part of undergraduate medical education. This is not sensible when you consider the figures from the British Pain Society³¹ stating that almost half of the population will experience chronic pain. The Advancing the Provision of Pain Education and Learning (APPEAL) taskforce therefore recommended the introduction of compulsory pain teaching for all undergraduate medical students. Might pain management become a core part of teaching for *all* health professionals?

Conclusion

Entwistle and colleagues¹⁴ note that living well with a condition requires service providers to move towards more positive views of people living with long term conditions. By positive, they are referring to viewing such people as "active partners or asset-bearing co-producers who themselves contribute to the solutions for their health problems." Such a move means that we as health professionals will be more likely to be better informed about the barriers facing our patients in their respective life contexts, and so more able to work with compassion and realistic recommendations.

And whilst it is true that there is a need for bigger systemic and policy changes to be implemented, there are always smaller steps that we can take, and maybe together these small steps will add up and make a bigger combined difference. As a minimum the least we can do as health professionals is remember that "self-management of chronic illness does not exist in a vacuum, but rather within the context of other people and influences" 10.

Addendum

This perspective piece was written before COVID-19 reared its ugly head. I hope that when we get through this difficult time, there will an opportunity to review our approach to pain management. There will be things that we have been forced to do as a consequence of the pandemic that may have shown us there are different ways of doing things. Right now though, our focus needs to be on doing the best we can in trying circumstances.

Executive Summary

Background: The numbers of people living with long-term conditions (including persistent pain) are increasing. Add to this the years of decreasing investment in our health system and it is not so surprising that the search for a solution has led to the idea that people with chronic conditions should play a more active role in managing their conditions. This has translated into 'self-management'.

Problem: Typically self-management involves the individual living with persistent pain taking responsibility for managing their condition. However, their ability to do so is not entirely under their own control. Typically self-management does not explicitly take into account the wider society in which we live, our financial and social capital (or lack thereof), or our health literacy. In other words, it ignores a person's wider life context.

Possible Solutions: A refocus, away from the current central focus on the self, towards collaboration ('collaborment), incorporating understanding of life context and focusing on living well with, rather than managing persistent pain.

Future Perspectives: We need to be working towards a relationship between health professionals and people living with pain which is a meeting between equals who have come together to pool resources in order to solve a problem. We need to ensure that the notion of collaboration is built into the health professional training programmes and move away from the traditional 'health-professional-knows-best' approach. We need to lobby and ensure that pain is a core part of all health professional training. Service providers need to move away from negative views of people with long term conditions, instead viewing them as collaborators who contribute to the solutions for their health problems.

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De Ruddere L, Goubert L, Stevens MAL, Deveugele M, Craig KD, Crombez G. Health care professionals reactions to patient pain: Impact of knowledge about medical evidence and psychosocial influences. J Pain. 15(3), 262-270. (2014).

This is a study that involved GPs and physiotherapists who were asked to watch video sequences of 4 patients who were manifesting pain. Each video had an accompanying vignette describing the presence or absence or medical evidence and psychosocial influences for pain. If medical evidence was absent, the health professionals perceived lower pain and daily interference, felt less sympathy for and had lower expectations of

medication impact. In other words, the patients pain was taken less seriously by the health professionals. The findings are described as being important to further understand the difficulties in the clinical encounter between people living with pain and health professionals.

Entwistle VA, Cribb A, Owens J. Why health and social care support for people with long-term conditions should be oriented towards enabling them to live well. Health Care Anal. 26, 48-65. (2018).

The authors of this paper invite the reader to consider that a change in focus is needed. One that moves towards a focus that enables those who live with long term conditions to live (and die) well with them. For example, disease control is of key importance to health professionals, but it may not be the topmost concern for the individual concerned who may feel that maintaining social roles, regaining identity and emotional balance is more of a priority. This paper is written with the aim of making the reader think and consider the benefits of opening up our current self-management focus so that as health professionals we see the whole person and not just the condition.

Francis H, Carryer J, Wilkinson J. Patient expertise: Contested territory in the realm of long-term condition care. Chronic Illn. 15(3), 197-209. (2018).

The authors based in New Zealand paper focus on the experience of the 'expert patient' in the context of self-management. The authors present 16 case studies collated over an 18 month period, plus an interview with the primary care clinician for each case. The paper has excerpts from the interviews which brings the points being made to life. The paper highlights a mismatch between how self-management is operationalised and what patients want and need.

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