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Self-Management: Bridging the Gap Between Rhetoric and Reality

As a Health Psychologist, with a special interest in improving care and support for people living with long-term conditions, I found Prof Rodham's 'Overrated' article a refreshing read. It has often struck me that, while enabling self-management is a laudable aim, there is a clear distinction between the rhetoric of self-management (how it is discussed by researchers and policy makers) and the reality (how the notion of self-management is translated into interventions and services). This distinction exists in part because we do not stop to question what 'self-management' actually is (or, importantly what it isn't), which means that academics, policy makers, commissioners, service providers, clinicians and service users often use the term in different ways. But, the distinction also exists because of the differing incentives and motivations of the groups involved – to understand why people are often not effectively supported to manage their condition, we have to think about why each of the groups outlined above would be interested in 'self-management' – what is it they want to achieve by providing, funding, or promoting 'self-management' and how does this fit with their wider responsibilities/aims/priorities?

I'll turn to the issue of definition first. Rodham's article refers to Sadler's definition of self-management as 'a process in which individuals acquire skills, strategies and knowledge to manage the physical psychological, emotional and social effects of a chronic condition' (Sadler et al., 2017, p1). Let's think about what this means for someone diagnosed with diabetes. What skills, strategies and knowledge do they need to manage the physical effects of their condition? Are these the same skills, strategies and knowledge that will help them manage the psychological, emotional and social effects of their condition, or are they different? Are the skills, strategies and knowledge they need specific to diabetes, or are these the same ones we all need to manage our physical, emotional and social wellbeing? What if they have other conditions too? Do these require a new set of skills, strategies and knowledge, or is there some carry over? What if their condition changes, or they start a new medication? More fundamentally, do any of us even know how to make sure we are always in optimal health physically, psychologically, emotionally and socially? Is this achievable/realistic, or will we all most likely have days when we are feeling upset/angry/isolated/frustrated/tired/unmotivated/fancy a chocolate biscuit/glass of wine? If we don't think perfect self-management is realistic, then what is it we are aiming for and what is it we expect of people living with long-term conditions? How do we know if a person is effectively self-managing and how do we know when they are not? At what point is intervention necessary/desirable and what form should this intervention take?

As my ramblings hopefully illustrate, even a single seemingly-simple definition can throw up a host of questions for which there are few clear answers. And, of course, there are plenty of other definitions of 'self-management' in the literature. In the case of diabetes, research has helped to elucidate some of the questions outlined above. For example, Hinder and Greenhalgh (2012) conducted an incredibly valuable ethnographic study of diabetes self-management aptly titled 'This Does My Head In'. Following 30 people with diabetes at home and in the community, they revealed an extensive range of practical, cognitive and socioemotional tasks involved in day-to-day 'self-management', concluding that self-management was 'hard work' and was enabled or constrained by economic, material and socio-cultural conditions within the family, workplace and community. For some, capacity to self-manage was limited by co-morbidity, cognitive ability and psychological factors. The consequences of self-management efforts strongly influenced people's capacity and motivation to persist. So, what can we take home from this? If you want to know what it means to self-manage a long-term condition, ask people living with that condition and don't expect a short answer (so qualitative research and patient and public involvement (PPI) are vitally important). It's incredibly difficult and it involves every aspect of life (so emotional and psychosocial support [as well as compassion and empathy] are essential components of routine care), the range of knowledge/skills required to self-manage is vast (so patients need to know how to access information and support that is relevant to their needs), success or otherwise with self-management-tasks is not just down to the individual (so individual-level interventions are unlikely to be sufficient on their own), there may be lots of other support needs that must be met to enable self-management (so we need to be thinking integrated care, not just stand-alone interventions), people's needs will change over time (so think long-term support over the person's lifetime), clinicians need to be aware of the implications of unsuccessful self-management efforts and be able to work with people to recover from these (or, to borrow from Rodham's analogy of learning to ride a bike, they need to be able to help the cyclist back up when they wobble/fall down, to do so sympathetically, and be willing to do so again and again, for as long as it takes for the cyclist to feel confident to go it alone). None of this sounds like a "quick-fix-here's-an-app-and-bunch-of-leaflets-and-off-you-go" solution. And that's because it isn't. While information provision (that is timely and relevant to the individuals' specific areas of concern) is an important component of self-management support, in broader terms it is about supporting people to live their lives the way they want to in the context of an incurable condition that is never going away and is an absolute pain in the neck.

I'll turn now to the issue of motivation and incentives. That is, why should policy makers, commissioners, service providers and clinicians be concerned about self-management? All of these

groups are concerned with improving health and wellbeing and in this sense there is a shared agenda with the person living with a long-term condition. However, there are other agendas too – the need to rethink healthcare in the context of an ageing population with increasing numbers of people living (and living for longer) with long-term conditions and complex comorbidities, the need to provide self-management support in the context of limited financial (or other) resources, the need to cope with increasing demands and clinical loads (“*and now I’m supposed to provide self-management support as well?!*”), the need to know how to manage the ‘difficult patients’ who don’t seem to follow advice, no matter how many times you tell them to lose weight, avoid stress and do more exercise. These competing agendas often mean that ‘self-management’ becomes a proxy for shifting responsibility for health improvement away from formal services (as far as possible) and towards the person living with a long-term condition (and/or their carers). Essentially it becomes their ‘job’ to self-manage and to do it well, with minimal cost to services.

As psychologists we must be aware of the needs of those delivering, providing and planning care as well as the needs of service users, we must also understand the contextual factors that can constrain efforts at every level and work closely with stakeholders to develop interventions and approaches that are realistic and achievable, we must work at multiple levels to achieve whole systems change. We also need to think about how we communicate psychology theory and concepts, so that these can be translated into practice. Much of what I have described above is really about building ‘self-efficacy’ i.e. enabling patients to feel confident in their ability to undertake the complex range of tasks involved in managing their condition on a day to day basis, according to what the situation affords. Self-management programmes such as the Chronic Disease Self-Management programme¹ and Expert Patients Programme (EPP)² are designed to enhance patient self-efficacy by modelling self-management behaviours, enabling patients to develop mastery experience, providing supportive feedback and opportunity to express worries and concerns. However, the concept of self-efficacy has not yet filtered through to other elements of patient care (ask a person with diabetes if they have every been ‘told off’ for high blood glucose levels, or a smoker if they have been berated for failing to quit). It is also important to remember that self-efficacy is just as important for those providing care as it is for patients – we may know that information-giving (or telling) is rarely sufficient to change behaviour, but if we just tell clinicians this can we expect their behaviour to change? Instead of criticising clinicians for telling/berating, we need to work with them to develop the skills and confidence necessary to support patient self-management. We need to do so patiently and sympathetically, with awareness of the very real difficulties and limitations they face in their

¹ <http://patienteducation.stanford.edu/programs/cdsmp.html>

² <http://selfmanagementuk.org/>

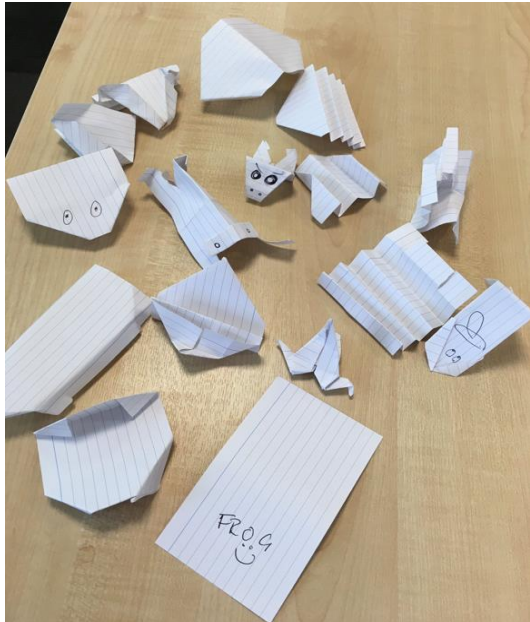
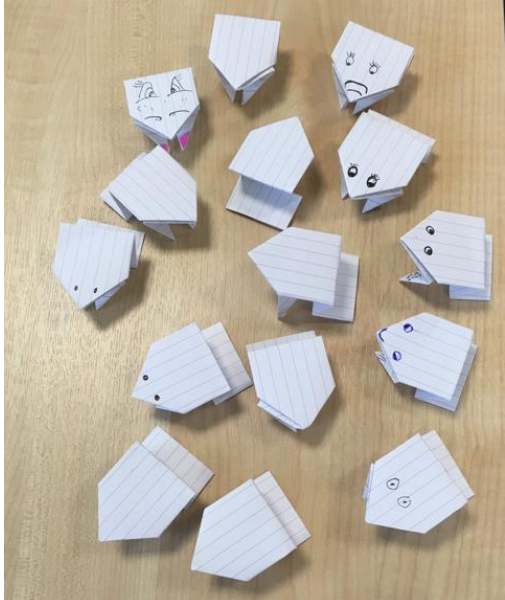
day-to-day work (see Reidy et al., 2016 for an insight into commissioners' experiences of self-management support).

But there is another problem we face here – convincing others of the need to know some of this psychology mumbo jumbo stuff. Why would a highly qualified health professional who is already very competent in their own field want to learn about self-efficacy? We can't just assume that everyone finds psychology theory and concepts as fascinating as we do. This is where a good analogy is often very useful. Rodham's example of learning to ride a bike neatly illustrates how unhelpful it is to criticise unsuccessful attempts at self-management – imagine yelling at a child every time they wobble/fall down – is this likely to build their confidence and motivation to succeed or have the opposite effect? It also illustrates why information-giving or one-off interventions are unlikely to be sufficient to master behaviours that require ongoing effort and learning – imagine just giving a child a leaflet on cycling/bike anatomy and expecting them to get it right first time. Learning to ride a bike is an experience most people can relate to, and we can draw on this experience to communicate psychology concepts in a way that resonates with the individual's lived experience – *Aha! So, this concept we are discussing is not just abstract theory, it is relevant to every-day life and useful. It explains why the approaches I've tried in the past are not working and provides a way forward.*

In our work training health professionals to support self-management, we have found an origami task helpful for explaining the concept of self-efficacy. Part way through a workshop on long-term conditions, we ask people to stop what they are doing and make an origami frog. We provide minimal instructions – it must look like a frog and be able to jump. Participants are instructed to work individually and not help others if they get stuck. After a couple of minutes, we ask them to stop and present their frogs and then we ask what thoughts and feelings they experienced during the task. We also ask participants to rate their confidence in building origami frogs on a scale from 0-10. The task is then repeated under conditions designed to build self-efficacy – modelling step-by-step how to create the frog, providing supportive feedback, encouraging discussion of difficulties/concerns and persisting until every person in the room has mastered the task successfully with plenty of support from the workshop facilitators and participants. We then ask them to present their new frogs, complete the thoughts and feelings table and rate their confidence in building origami frogs again. The figure below illustrates the type of responses we typically receive to this task, along with images of some of the origami frogs. Although this seems (and is) a trivial exercise, compared to the complex tasks involved in managing a long-term condition, participants report finding it useful for not only *understanding* the concept of self-efficacy, but also *experiencing* what it feels like to attempt new/challenging tasks without sufficient support.

So, what do we need to do to bridge the gap between the rhetoric and reality of self-management? Reach out, engage, communicate, understand and support. Be aware of differing motivations, incentives and constraints and find ways to work with these to achieve shared goals and objectives. Find ways to translate conceptual knowledge into concrete action (without oversimplifying, or implying a rigid one-size-fits-all approach). Be scientific, creative and innovative. But above all, in the context of so many competing priorities and agendas, ensure that the human experience of living with a chronic condition and its multiple impacts on day-to-day life is not forgotten.

Figure 1. Origami Frogs Created Before and After Building Self-Efficacy

| | |
|--|---|
| <p>Before</p> <p>Thoughts "I cant do this" "I give up" "I'll just 'fudge it'"</p> <p>Feelings Frustrated Irritated Despondent</p> <p>Confidence (0-10) Typically around 0-2</p>  | <p>After</p> <p>Thoughts "I've done it!" "It actually jumps" "I quite like my frog"</p> <p>Feelings Pleased with my efforts Supported Happy</p> <p>Confidence (0-10) Typically 10</p>  |
|--|---|

NB. Note how varied the frogs in the 'before' condition are. How might this reflect the range of ways patients attempt to 'do self-management'? How might the thoughts/feelings illustrated above influence future efforts? Why might some people be more confident than others at baseline?

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