

Working to manage chronic illness in daily life

Anne Townsend

"It is impossible not to manage ones health, the only question is how one manages." (Lorig & Holman, 2003, p. 1).

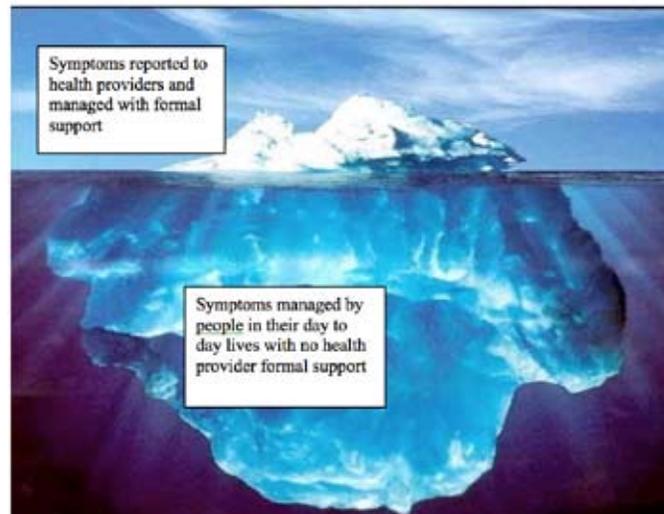
Self-management of chronic illness extends beyond managing disease to managing the impact of symptoms on everything we do (our occupations) and daily life. Self-management has become a cornerstone of public health strategy due to the rising rates of chronic illness. Programs and initiatives flourish and there is an increasing demand for allied health professionals to support individuals in their response to chronic illness (Health Council of Canada, 2010). Because of their understanding of the relationship between functional ability, illness, the environment, and personhood, occupational therapists can play a key role in providing such support.

It is well documented that those who seek care only represent the tip of the iceberg and health professionals see only a small proportion of the symptoms and illness people experience. Evidence from the United Kingdom (UK) shows that people with chronic conditions actively engage in complex and varied self-management strategies and use the family physician consultation as a last resort (Townsend, Wyke, & Hunt, 2008). In short, people use skills and resources to manage as best they can without using health services:

...the universal experience of symptoms of illness does not translate automatically into demand for care. Only a small proportion of symptoms which people experience are presented to the general practitioner. The large number of symptoms dealt with, without medical care has been termed "the illness iceberg" or the "symptom iceberg" (Campbell & Roland, 1996, p. 75)

Research shows that people with chronic conditions do different types of work: work to manage the symptoms, the medicines, the treatments; work to manage occupation and continue 'normal' daily life; and work to maintain their familiar identities (Corbin & Strauss, 1988; Townsend, Wyke, & Hunt 2006). This self-management 'work' occurs in the context of health system transformation. Health policy now recognises people's existing skills, practices and tendencies to self-manage (Wyke, 2006). There has been a shift from the notion of a passive patient to a more active partner in healthcare, working alongside the healthcare team to enhance the experience of chronic illness (Wyke, 2006). It is also hoped that increasing patient self-management can ease the economic burden imposed on health systems by the rising rates of chronic illness.

This article draws on a qualitative study about help-seeking in early rheumatoid arthritis (RA), a debilitating chronic condition. I report on individuals' accounts of self-management activities, in pre- and early post-diagnostic stages of RA. Aspects of their experiences have been reported elsewhere (Townsend et al., 2010).



Interviews

The Early Rheumatoid Arthritis Help Seeking Experience (ERAHSE) study examined the help-seeking process from symptom onset to one year after diagnosis of RA. Thirty-eight adults were recruited through medical offices and arthritis web-sites. Participants had all been diagnosed with RA in the previous twelve months, resided in British Columbia, were English speakers and were aged in their 30s to 70s. They came from a mix of household compositions and diverse employment circumstances; homemakers, retirees, those in employment (full- or part-time), or receiving sickness or disability payments. A topic guide was used to elicit detailed responses through in-depth interviews. Constant comparisons guided the thematic approach to analysis. Ethics approval was secured and informed consent obtained.

Findings

Participants described multiple and independent (unsupported by a health professional) management strategies to alleviate symptoms as they attempted to limit impact of illness on their daily occupations and lives. They were concerned to fulfill social roles and maintain favored identities. Themes generated from the interviews included self-management as: a) illness work; b) daily life work; c) identity work.

Illness work: Managing symptoms with no support

People undertook varied strategies to ease symptoms in their attempts to limit the impact of pain on daily life. Often they were averse to relying on medications. They sought information about alternative medications and treatments as

they faced debilitating pain, which impacted negatively on function. They expressed a stoic approach, and determination to 'push through' the pain or fatigue and 'carry on' or 'keep going' with occupations in order to avoid disruption of daily life and continue in their roles and with leisure activities. However they were frustrated at their attempts and typically they had no formal guidance or support (beyond prescribed medication) prior to getting a diagnosis, and often subsequent to receiving a diagnosis. One participant, Rain, noted how he was unsupported while waiting nearly a year to see a specialist, while another, Nora, lacked support post diagnosis:

The GP he... hasn't directed me in something else I could do in the meanwhile other than just taking medication; so that I am not too happy. I have been doing a lot of walking. That's about it. ... Someone mentioned swimming. I should get into that. The problem is you're kind of in the middle waiting, you know. (Rain)

I had researched... the medication and I just didn't want it.... So I went to a naturopath, I went to acupuncture, I did lots of diets and you hear from people you... should take this kind of pill... So I tried everything... everybody said. But... nothing really helped.... I thought: "I need help... somebody has to do something." (Nora)

Everyday life work: Bad days, worse days

In order to function in their day-to-day lives participants 'worked hard at self-management'. They undertook multiple combinations of strategies and a range of diverse management techniques in order to continue familiar occupations. They described the importance of: a positive attitude, over the counter medications, pacing, resting, reorganizing tasks and having family support. Often participants expressed having to scale back or stop activities or 'push through' pain in order to 'keep going'. Such activities included personal care (e.g., getting dressed, continuing in employment, parenting tasks or leisure activities). One participant described how she self-managed in multiple ways, with no professional support as she faced debilitating, painful and ongoing symptoms and struggling to continue working alongside her husband in the family cafe:

"I was limping like you wouldn't believe... in the cafe... it can get pretty high paced... it's just my husband and I and so it can be very... stressful... you want to give the service... I was hobbling a lot. So I would change the shoes... Well these shoes will work better for now... these shoes are good when my ankles are sore and these shoes are good for when my toes are really sore... And I slept... a lot. Any time I could. My husband actually has an easy

chair for me in the bath so I can put my feet up. So when we're not busy at the cafe I would be in the bath sleeping..." (Barbara-Anne)

Others talked of not knowing what activities would help, or how far they should push their bodies. Rain, reflecting on his year wait for the specialist commented:

You want to do it but you want to wait for the doctor's advice or the specialist's advice... you try to push your body but then you start thinking in the back of your mind, what is your limit? And like I say you get into doing physical activity at work and you feel a little bit of pain because you're lifting heavy objects. ... I went on the Internet to look for some support. (Rain)

Identity work

The majority of participants expressed that being able to continue with meaningful occupations was fundamental to their identity and sense of self. They self-managed in order to function in particular roles which defined them. Many expressed the importance of keeping active and continuing meaningful occupation in order to fulfill roles central to their identities:

You've got inflammation, you read it in the newspaper... try this... it's a remedy and anything like that. ... in the back of my brain I kept thinking... I've got to keep moving... I like being active. I am not the type to sit and just watch a movie... I don't want to just sit and do nothing... I can't. That's not me... Especially because I am in the service industry and I want to make sure people are enjoying their visit at the cafe. It's just the type of nature I am... I'm more of a caregiver kind of personality. (Barbara-Anne)

Discussion

Strauss and Corbin describe living with chronic illness as 'unending work' (1988). Self-management must not mean 'unending work' as individuals strive to live their daily lives with little or inadequate support. People self-manage but they need support to manage effectively. People often don't have access to information or resources or supportive interaction with appropriate health professionals. In such cases, they may become more disabled, rather than enabled with professional support (Wyke, 2006). Currently, health systems are not organised in ways that enable people to maximise their skills and self-manage as effectively as they are able. Rather than formal care and self-management being mutually exclusive, they can be regarded as a combination of interconnected resources. Health professionals, occupational therapists in

About the author

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particular, have a pivotal role to play in providing people with the support that they need to manage to optimum capacity.

People and patients must be respected as co-producers of health and health care who will work with appropriate health providers to maintain health, prevent and treat illness and manage its impact in everyday life (Wyke, 2006). Occupational therapists are known for their client-centred focus to supporting people to engage in meaningful and desired occupations. Building capacity and capability amongst occupational therapists to support people to self-manage the impact of a chronic condition on daily life is a natural extension of current practice.

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