A focus on the issues associated with implementing self-care as an intervention

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Introduction

It is generally well understood that people with impaired nerve function are required to adapt to their disadvantage. Adaptation includes harnessing alternative resources to substitute for the loss of sensory, motor and autonomic modalities. It is also generally well understood that alternative resources include using other senses more acutely: sight substitutes for sensation as a warning of tissue fatigue, applications of water and oil substitute for loss of autonomic skin maintenance, and exercise substitutes for agonistic muscle function that prevents contracture and deformity. For people affected by leprosy, essential actions taken to substitute for the loss of normal function fall in the domain of self-care.

Self-care has been extensively promoted and is established as a key part of the mantra of POD for people affected by leprosy. Dr Paul Brand tirelessly sought to educate health workers and leprosy affected people alike to encourage self-care practice. Jean Watson presented practical guidelines that have been a standard text since they were first published 1986. Thousands of workers and perhaps hundreds of thousands of people have been made aware of the need to adopt self-care practices; yet hundreds of thousands of people have nonetheless neglected to apply the advice and have struggled through life with worsening disabilities.

This paper therefore will not focus on methods of self-care, but will seek to open and begin to address the following questions:

- Is self-care a valid option?
- Why don’t people adhere to self-care advice?
- What can be learned from people who do adhere to self-care practices?
- How can lessons be applied to affect better results in future?

Is self-care a valid option?

The management of chronic conditions is a task of enormous proportions for health care policy makers globally. The contribution of non-communicable conditions and mental
disorders to the global burden of disease in 2002 was almost 50%. By 2020, the same issues will account for 60% of the global disease burden.\textsuperscript{2} The inadequacy of former models of health delivery to manage the burden was recognized by the WHO which collaborated with MacColl Institute for Health Care to develop a model that has been named the Innovative Care for Chronic Conditions (ICCC). The ICCC is a development of an earlier model, the Chronic Care Model (CCM). The essential feature of the CCM is that productive interactions between appropriately informed people and adequately prepared practice teams of health workers are developed. The ICCC is a development of the paradigm in which community partners are also recognized as essential players. The model functions optimally when all members are appropriately informed, motivated, and prepared with ‘skills’ necessary to manage chronic conditions. A notable challenge in accepting the model will be the development and application of the ‘skills’ that will be necessary.\textsuperscript{2,3}

What the model emphasizes is that self-care will become central to the development of health provision for people affected by chronic conditions. This is a growing reality in the developed countries where ‘Information Age’ medical models are becoming the norm, but it is still an embryonic concept in developing countries where ‘Industrial Age’ health structures still prevail. The issue is that as a concept, self-care is at variance with ‘Industrial Age’ models of health delivery.

Where Industrial Age Medicine is the norm, physicians and health workers are considered experts. Patients bring nothing to the interaction other than their illness. Definitions of health and illness, however, have changed (as acknowledged in the Ottawa Charter and the International Classification of Function). The ICCC paradigm reflects such changes and implies that whilst professionals are experts about diseases, people are experts about their lives. With this perspective, physicians can add medical expertise to that which people know about their lives to help people to create plans that will help them achieve their own goals. People with chronic conditions become their own principal caregivers with health care professionals as consultants supporting them in the new role.

In the context of the above model, Bodenheimer \textit{et al.} made specific reference to ‘self-management’ education, emphasizing that effective ‘self-management’ requires that patients are facilitated to learn problem solving skills that are useful for them to understand problems from their own perspective, and to use action plans to find solutions. They also emphasized that the skills need to be transferred in such a way that people are able to apply them to three aspects of chronic illness: medical, social and emotional.\textsuperscript{4}

Bodenheimer \textit{et al.} recognized that their recommendations would be difficult to implement and identified three barriers that impede the process of self-management education. One of the impediments to self-management education that they identified hardly applies to people with chronic conditions in developing countries (i.e. most private health insurance companies fail to reimburse self-management education). The other two points they identified are generic and are very applicable:

1. A lack of trained personnel has resulted in a dearth of self-care management courses.
2. People with chronic conditions have been socialized into the medical model which fosters dependence on professionals and is at variance with the concept of self-care.
Why don’t people adhere to self-care advice?

It is important to realize and accept that patients are in control of essential self-management decisions. When patients leave health facilities they can, and do veto recommendations health professionals make. An important finding from health behaviour research is that imparting awareness and information in isolation is insufficient if we are to hope for adherence to essential self-care practices.

Behavioural change is facilitated primarily by a personal sense of control, i.e. if people believe that they can take action to solve a problem instrumentally, they become more inclined to do so and feel more committed to such a decision. People who believe that they are able to cause events do conduct more active and self-determined life courses. The ‘I can do it’ conviction reflects a sense of control over one’s environment.

In the 1970s, Albert Bandura introduced the concept of perceived self-efficacy; high levels of which has subsequently been found to be related to better health, higher achievement, and more social integration. The concept has been applied to such diverse areas as school achievement, emotional disorders, mental and physical health, career choice, and sociopolitical change, but the areas of highest relevance to the discussion on self-care adherence is its influence on the adoption, initiation, and maintenance of health behaviors (cited by Shwarzer and Fuchs).

Locke and Latham (cited by Shwarzer and Fuchs) found that self-efficacy levels will either enhance or impede the motivation to act. They ascertained that people with high self-efficacy choose to perform more challenging tasks and that, not only do such people set themselves higher goals, but they also persevere with them. The explanation given for this is that, before people act, they anticipate either optimistic or pessimistic outcomes, relative to their levels of self-efficacy. Having embarked on an activity, people with high levels of self-efficacy invest more effort and persist longer than those with low self-efficacy. Self-efficacy has also been found to be associated with people who tend to select challenging settings, explore their environments, or create new situations. Furthermore, people with a high sense of self-efficacy are associated with an ability to recover quickly from set backs and are not easily diverted from their goals. Schwarz and Fuchs make an important point; they emphasized that self-efficacy leads to venturesome behaviour within the reach of an individual’s capabilities, but it does not lead to unreasonable risk taking. It is not the same as positive illusions or unrealistic optimism because it is actually based on experience (a progression through increasingly ambitious objectives that may start with a relatively modest goal).

According to social cognitive theory, human motivation and action are extensively regulated by forethought. This anticipatory control mechanism involves three types of expectancies: (a) situation-outcome expectancies, in which consequences are cued by environmental events without personal action, (b) action-outcome expectancies, in which outcomes flow from personal action, and (c) perceived self-efficacy, which is concerned with people’s beliefs in their capabilities to perform a specific action required to attain a desired outcome.

The Health Action Process Approach (HAPA) represents a development of the theory by Schwarz and Fuchs. Its basic precept is that the adoption, initiation, and maintenance of health behaviours must be explicitly conceived as a process that consists of at least two stages, a motivation phase and a volition phase.
THE MOTIVATION PHASE

Initially, individuals make assumptions about the possible consequences of behavior, e.g. ‘soaking feet means no cracks, so I should soak my feet’.

Based on the information processed, an individual then forms an intention to either adopt a precaution measure or change risk behaviors. The intention is dependent on three major cognitions:

**Perceived self-efficacy**

‘I am certain that I can soak and oil my feet daily even though I have to work.’

Essential perceptions would be: not at all true, hardly true, somewhat true, very true.

**Perceived outcome expectancy**

‘If I would soak and oil my feet daily, then it would reduce my risk of cracks.’

Essential perceptions would be: not at all true, hardly true, somewhat true, very true.

**Risk perception**

‘What is my risk of getting infection from cracks.’

Essential perceptions would be: very low, low, high very high.

A minimum level of threat or concern must exist before people start contemplating the benefits of possible actions and ruminate on their competence to actually perform them. However, evidence suggests that the influential role of threat or risk perception in the motivation and volition process has been overestimated in past interventions. Fear appeals are of limited value. Under conditions where individuals have no experience with the behaviour they are contemplating, outcome expectancies probably have the strongest direct influence until a sufficient level of experience is attained; then self-efficacy has by far the greatest independent effect.

THE LINKAGE BETWEEN PHASES

After a preference for a particular health behavior has been shaped (during the motivation phase), the intention has to be transformed into detailed internal instructions: how to perform the desired action and how hard and for how long an individual will persist (individuals subsequently enter the volition or action phase of health behavior to act out the intentions with the strategies that they have formed).

It is the degree of perceived self-efficacy that determines the number and quality of action plans that are developed.

THE VOLITION PHASE

This was developed by Shwarzer and Fuchs after the relapse prevention theory of Marlatt and Gordon, the volition theories of Heckhausen and Kuhl, and the self-efficacy theory. Outcome expectancies have very little independent effect on actions or perseverance in the volitional
Further factors that affect actions and perseverance

OPTIMISM

People with an optimistic sense of self-efficacy, visualize success scenarios that guide their actions and let them persevere in face of obstacles. When running into unforeseen difficulties they quickly recover. Such optimism is also termed ‘functional optimism’ which is different from ‘defensive optimism’.

Defensive optimism is a characteristic of people who feel less vulnerable towards health threats than they should, and they believe that peers are at greater risk of disease than themselves: ‘It will never happen to me so I won’t bother taking any precautions.’

Functional optimism is the product of high self-efficacy and outcome expectancies: ‘I know I can do this because I want to do it and know from experience that it is good. If I do it, I can look forward to better function.’

Individuals who are dominated by self-doubts are more inclined to anticipate failure scenarios, and become fretful over imagined performance deficiencies. Such effects lead to pessimistic people aborting their attempts prematurely.

Previous interventions have focused on risk communication to lower defensive optimism; the idea was to let people understand how much they really are at risk. Such intervention strategies were not very successful. Social Cognitive Theory emphasizes the opposite strategy by making people understand what they are able to change. Individuals should not only understand what they may lose, but they should also be challenged by what they could gain.

SETTING OBJECTIVES

When individuals set objectives on an ascending scale of difficulty (starting with easily achievable goals) it helps them to strengthen their self-efficacy convictions and assists them to eventually cope with greater challenges. This process is enhanced by internal coping dialogues: e.g.

- Making favorable social comparisons (‘I am looking better than those who don’t do what I am doing because of these actions.’)
- Referring to self-concept (‘I am worth the effort.’)
- Pulling themselves together (‘I am not so weak that I can’t do this!’)

Developing such cognitive skills and internal coping dialogues, particularly when matched to specific risk situations, makes control over urges to quit progressively easier.
PEER PRESSURE AND SOCIAL SUPPORT

Peer pressure and social support have been shown to have predictive power on behavioral changes. However, it appears that these too can be confounded by self-efficacy. The degree to which an individual is affected by peer pressure, or the extent to which an individual develops social support mechanisms is dependent on that individual’s self-efficacy resources: e.g. ‘They don’t want me to do this, but I can cope with their criticism’, and ‘I am not too shy to join the support group’.

ENVIRONMENTAL BARRIERS

When situations are overwhelming, meta-cognitive skills like those introduced above will fail to protect individuals. Actions are influenced by the perceived and the actual environment: e.g.

- A dominant other prohibits the desired behaviour.
- Situations where survival is threatened.

What can be learned from people who do adhere to self-care practices?

In his review, Bhuyan revealed a considerable body of evidence to support the efficacy of self-care as an intervention for a wide range of specific chronic disorders. Published evidence supporting self-care practice for people affected by leprosy, however, is scarce. Evidence from Nepal demonstrated that intensive self-care training does reduce the need for hospital admissions for ulcer treatment. Other studies showed that self-care did control impairments amongst people who had joined self-care groups in Nepal and Ethiopia. A number of provinces in China had implemented POD programmes in which self-care was the primary intervention. The results from the programme in China also suggest that, when assiduously applied, self-care is efficacious.

The author has had intimate involvement in self-care programmes in Nepal and China and submits observations from two programmes that were opposite in their approach to institute self-care yet similar in their impact on impairments. In Nepal, the emphasis was on internal empowerment so that people could assume control. Going beyond the essentials of risk awareness and necessary self-care activities, people were taught problem solving skills and social skills. They were given opportunities for basic literacy training and assistance to set up micro credit unions. They were also encouraged to actively plan and pursue activities that would benefit their general communities. Impairment control in these groups was excellent.

In Guizhou province, leprosy doctors were trained in necessary skills that have to be imparted to people adversely affected by leprosy. They were given responsibility for ensuring that self-care was taught to people living in remote leprosy villages. They were also responsible for monitoring and supervising the programme. Some offered small incentives to those who were found to have been applying self-care skills, but some also used the threat of withholding subsidies if the people did not comply. The results of impairment control were also excellent.

An interesting observation that applied to both groups was that people generally did not initially believe that self-care would actually be effective. In Nepal, people persevered because of peer support. In China they persevered because they felt compelled to do so. However, both
groups reported that after 6 months, they began to realize that self-care was effective because they had the evidence in their improved physical condition. With the evidence they could relate to, they were convinced of the efficacy of the intervention and reported that they would continue with the intervention regardless of whether they had other motivating factors or not. It was also reported from both groups, that one of the most satisfying aspects of the programmes was that they had controlled their impairments themselves.9,10

The author suggests that the finding stated above supports the theory on which the Health Action Process Approach (HAPA) is based.6 Self-efficacy was developed on the strength of experience. Having persevered for a period of 6 months, the people in both programmes were able to recognize that their actions had yielded positive results. The realization that they had accomplished the improvement independent of any medical intervention, revealed their latent self-efficacy. The realization of their own ability to control their impairments produced optimism and proved to be the impetus for sustained commitment.

**How can lessons be applied to affect better results in future?**

**GENERAL PRINCIPLE**

If self-care practice is to become a reality of health behaviour, it is imperative that programmes acknowledge and address the issue of control. If people with chronic conditions are to be recognized as their own principal caregivers, programmes should focus on facilitating the realignment of health care professionals’ roles so that they become consultants who facilitate and support people as they take on the role of principal caregiver themselves. That programmes based on industrial age models of health delivery are inappropriate for the management of chronic conditions is an issue that has been recognized by the WHO. The WHO actively promotes the application of the Innovative Care for Chronic Conditions (ICCC). This model emphasizes the centrality of self-care and acknowledges the active participation of the affected person, health professionals and community members (or family).3

**SPECIFIC ISSUES**

- Environmental barriers (physical and social) need to be recognized and addressed.
- The first 6 months of self-care application are vital to an individual’s subsequent decision to continue the practice. Appropriate support needs to be applied during this period to ensure perseverance which will awaken an awareness of self-efficacy. Once established, self-efficacy will be the primary dynamic that will continue to drive self-care practice.
- Efforts should be made to stimulate and strengthen self-efficacy. The application of empowerment principles would be very useful in this regard.14 The principles of empowerment are: the establishment of a positive identity, inculcation of the value of life and the pursuance of aspirations. The affects of internal empowerment are closely allied to affects that result in desirable health behavior as described in the Health Action Process Approach (HAPA).
- Beyond the necessary knowledge relating to disease specific characteristics, self-care education requires that people are assisted to learn problem solving skills that are useful for them to understand problems from their own perspective, and to use action plans to find solutions. Individuals should be helped to set objectives on an ascending scale of difficulty.
(starting with easily achievable goals) which will enhance the awareness of their self-efficacy and should assist them to eventually cope with greater challenges.

- Skills should be developed and transferred so that people are able to address all three aspects of chronic illness: medical, social and emotional.
- Community participation, in the form of moral support and encouragement does impact positively on self-care practices. Advocacy for such support should therefore be considered when planning self-care interventions.

Conclusion

Self-care for people challenged by chronic health conditions is not an option; it is an imperative. Self-care is a viable intervention, but the application of the intervention does not fit easily within existing health provision structures. The fundamental issue is that many programmes in developing countries are not yet prepared to face the challenge of a paradigm shift from industrial age health care provision, to the more inclusive information age models (e.g. ICCC). This is an essential development that needs to be reality at all levels of programme provision if self-care is to be a successful intervention.

Programmes that adopt a commitment to self-care will require access to resources, including development opportunities, self-care education trainers and opportunities for operational research for context specific situations. NGOs should make the provision of such resources a priority.

References