Exploring the role of self-management programmes in caring for people from culturally and linguistically diverse backgrounds in Melbourne, Australia

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Abstract

Background Chronic disease self-management programmes are now an important adjunct to the treatment and care of Australians with chronic illnesses. Most programmes are delivered in English and cater for 'Anglo' views of health and illness. The Peer-Led Self-Management of Chronic Illness Project was funded by the National Health and Medical Research Council (NHMRC) to test the hypothesis that the Stanford University Chronic Disease Self-Management Program would improve health outcomes for people from the Vietnamese, Greek, Chinese and Italian communities in Melbourne's north-eastern suburbs.

Objective To examine the extent to which the programme required modification so that the concepts associated with self-management programmes have relevance to the health behaviours of people with chronic illness from the above communities.

Methods Four focus groups facilitated in English, using interpreters.

Results There was wide understanding of the concepts employed in self-management programmes. Literacy problems emerged as the major obstacle to participating in unmodified programmes.

Conclusion The conceptual aspects of the programme require less modification than originally predicted, but the programme requires sensitive modification so that it is accessible to people with low literacy levels.

Introduction

Self-management programmes have consistently demonstrated good outcomes for people with chronic illnesses,[1] enhancing participants' self-efficacy and personal control, through strategies of persuasion, observation and direct practice.[2] Such programmes are increasingly important in managing chronic illness in Australia, the US and the UK.[3,4] However, with some exceptions, these programmes are delivered to people who are predominantly educated, well-resourced and English-speaking, who relate strongly to the values of individualism, self-determination and independence on which these programmes are based.[5] Attendance of participants already predisposed to the benefits of such programmes further reinforces the good results shown in randomized-controlled trials. The consistent reporting of benefits of self-management[3] may be related to both socio-economic status and cultural factors.

Given that Australian government[6,7] now support the development and promotion of self-management programmes as part of chronic disease management, there is a need for research that evaluates the impact and outcomes of self-management programmes generally as well as in more diverse cultural, social and economic settings.[1]

The Peer-Led Self-Management of Chronic Illness project is currently attempting to evaluate the benefits of the Chronic Disease Self-Management Program (CDSMP) for people from cultural and linguistic backgrounds other than English. The specific target groups are people from Chinese, Italian, Vietnamese and Greek backgrounds who have a chronic illness, and live in the north-eastern and inner eastern suburbs of Melbourne. The hypothesis that self-management programmes will benefit people from other cultures will be tested in a randomized-controlled trial, where the CDSMP will be delivered in Chinese, Italian, Vietnamese and Greek by bilingual peer leaders (that is, people from these cultural backgrounds who have a chronic illness) to 800 participants.

While this programme has been delivered overseas in Spanish[8] and Chinese,[9] its delivery in other languages has never been thoroughly tested with Australian communities.

Culture and ethnicity clearly shape attitudes and beliefs about diseases, health and health care.[10,11] For example, there is a relationship between one's cultural affinity and perception of and response to pain.[12,13] Payer[14] has demonstrated marked differences in health beliefs and clinical behaviour in the USA, UK, France and Germany, suggesting cultural determination. Awareness of the cultural context of health care is critical to effective patient-centred care.

In attempting to deliver the CDSMP in cultural settings important issues arise. The first issue can be broadly described as one of access and equity. In 2001, there were over 3.5 million people living in Australia (28%) who were born in countries where the first language was not English.[15] For many such people, access to health services is a major issue. A longitudinal study of immigrants to Australia found that predictors of health services use were gender, age, English proficiency and visa status.[16] Specifically, having limited English proficiency and lack of family support were identified as being common barriers to accessing health services.

Another factor that affects those from culturally and linguistically diverse backgrounds (CALD) accessing health services is the provision of information on health services. Documents containing information about health services assume a certain level of literacy, be they in English or in an immigrant's native language. A report by the Australian Bureau of Statistics (1996) found that of people who did not speak English as their first language, approximately 45% had very poor skills in English and some 25% of people had poor literacy skills in their native language.[15] These people experienced considerable difficulties using many of the printed materials encountered in daily life.

A second issue concerns the assumption that a uniform application of a self-management programme across populations will produce consistent and uniform benefits, such as reducing inappropriate health service utilization.[7,15] Programmes that are based in Anglo-centric values may have little relevance in communities where beliefs about health and illness are not traditionally mediated by beliefs about self-determining actions.[17]

Promotion of self-management programmes is primarily to the English-speaking population, there are few programmes developed to embrace the diverse cultural contexts in which chronic illness may be experienced. Thus the problem continues, that while some 28% of the population is from CALD background,[15] their access to current programmes is limited by Anglo-centric promotion, delivery in English and a lack of investigation into whether such programmes are culturally relevant.

The first step in the research required translations of the CDSMP materials into the four languages. Consultations about the translations with health professionals suggested that self-management programmes would not be well attended by people from CALD communities for a variety of reasons. The most common reasons suggested for potential failure were: self-management was an alien concept, as people only respected advice proffered by experts; fatalistic attitudes towards illness and death in other cultures make self-management an unlikely option and those most in need of self-management programmes were not educated well enough to adopt the strategies. In order to optimize the success of the project, measured in terms of attracting numbers of people who otherwise would not normally attend, it was decided to explore some of the concepts integral to the CDMSP with focus groups containing members of the target groups. The results of the focus groups were used to modify the CDSMP to meet the cultural sensitivities of people from Chinese, Italian, Vietnamese and Greek backgrounds with a chronic illness.

Methodology

Focus groups are the ideal means for conducting developmental research such as this.[18–20] They offer the opportunity to validate the perceptions and attitudes of health professionals regarding the CALD clients' self-management skills.[21] The approach used in facilitating the focus groups involved a combination of both directive and non-directive approaches. This allowed for a certain amount of direction and structure to the discussions and enabled systematic and comprehensive interviewing across the language groups.[22]

Aim of the focus groups

The focus groups aimed to (i) test the proposition that self-management programmes were relevant to each community; (ii) alter the CDSMP so that it incorporated the cultural concepts suggested by the group and (iii) gain first hand knowledge of any barriers to people attending programmes.

Recruitment of participants

Focus groups were conducted for people from Chinese, Italian, Vietnamese and Greek backgrounds. A total of four focus groups were run, with the average size of the groups being six participants. Each focus group was gender balanced with overall ages ranging from 55 to 82. The conditions included arthritis, asthma, cardiovascular, Parkinson's disease, diabetes and chronic back and joint pain. The sessions were held in local community venues where participants were comfortable.

Focus group participants were recruited from ethno-specific elderly citizens clubs, an aged care facility and community health centres exercise classes. Club presidents and health professionals identified potential participants. Each participant received a small honorarium to compensate for their time and expenses. Morning teas were provided.

When working cross-culturally there are numerous issues that must be considered.[23] One concerns the use of interpreters or conducting the focus group in the participants' language. If interpreters are used then problems of translation during the focus group arise, while problems of translation arise at the time of transcription in the latter case. In this instant, we decided a staff member would facilitate the focus groups using an interpreter, as we needed to explain the concepts of self-management and their relationship to the broader health services. This resulted in an uneven quality of data, across the focus groups, as the interpreters' approach to their instructions was highly variable.

Focus group questions

Another problem concerns the design of the questions so that they elicit the information required, but are culturally relevant for the participants. Questions were framed following consultations with groups of ethno-specific health workers and consumer representatives, who considered attitudes and beliefs about illnesses would be a barrier to some self-managing ethnic groups. Questions were asked about how illness impacted on the person's life and whether the person took steps to ameliorate that impact. Other questions related to whether illness was seen to be part of a broader belief system. The concepts central to the CDSMP were explained and participants were asked if they thought such programmes would be of assistance to them, in improving their lives.

Data were recorded in English, although Knodel notes ideally that the data should be recorded in both the language of the participants and a common language.[22] Due to cost and time issues this technique was not used. The authors acknowledge that the responses may have been different if the groups had been conducted entirely in the participants' own language.

Once collected, a content analysis of the data was performed.[24] This meant that it was possible to analyse the data in the context of the attitudes the participants expressed towards being ill, their experience of the Australian health system and towards the concepts of self-management.

Results

Chinese focus group

Half of the participants described chronic illness as an illness that lasted a long time and could become progressively worse. Medical treatment was of little use in chronic illness. A view emerged that a chronic illness meant that it was necessary to pace themselves, according to their body's needs. Part of pacing oneself included the concept of emotional balance or maintaining a 'light heart'.

The group was divided over the measure of control they could exercise in coping with their illness. For example, a woman with arthritis considered physical exercise was a great assistance while others with asthma felt they were at the mercy of the seasons.

The concept of self-management was relevant to this group. One person described his routine of self-monitoring his glucose levels, medication, diet and exercise, as well as maintaining a 'light heart' as self-management. Some participants saw these strategies as adjuncts to their medical care, while others saw it as the primary form of their care. Only one participant regularly used traditional Chinese medicine and this was as an adjunct to Western medicine. However, for the majority of participants self-management was limited to physical exercise. Making an action plan, the centrepiece of the CDSMP, was limited to physical exercise.

The group was at first divided over the value of peer leaders, some arguing that experts were better value leaders while others argued that peers had the advantage of shared understandings with participants. These views were adopted by the other participants.

Strategies central to this self-management programme such as positive self-talk and distracting oneself from pain and discomfort were all readily understood by the participants who were able to give their own examples of how they employed such strategies to their own advantage.

Vietnamese focus group

The Vietnamese focus group associated chronic illness with the amount and type of care they were likely to receive. A chronic illness was associated with 'lots of tests' and visits to the doctors.

A theme that was constantly revisited was the contrast in their care in Australia with the care they might have received in Vietnam. There was a degree of ambivalence associated with this. The relative lack of care in Vietnam had the advantage of leaving them in ignorance. In Australia, they perceived that doctors would continue to order tests until an abnormality was found. Anxiety was associated with this level of scientific medicine. While anxiety was also associated with their diagnoses, especially diabetes, this was compounded by the difference in lifestyle between Vietnam and Australia.

Participants referred to the amount of exercise, the fresh food and their active work lives in Vietnam. In Australia, they all tried to compensate for the loss of this lifestyle by adopting an exercise programme.

All the participants had recently used herbs and some had consulted traditional practitioners. This was another contrast between Vietnam and Australia. Herbal remedies and the expertise associated with them were readily available in Vietnam but this treatment was very expensive in Australia.

Action plans were understood in the context of physical exercise and taking medication. They were seen as a means to integrate a health regime into a relatively unorganized day.

The concept of self-talk in this focus group was described as 'positive thinking' and the participants interpreted this favourably as a form of distraction. Participants considered that avoiding situations that had a negative impact on them was a positive benefit and they spoke of activities such as volunteering, gardening, phoning family in Vietnam, as ways they distracted themselves from pain and worry.

> Whenever I feel worried about my health it helps to talk with my family. Before, it cost a lot to phone Vietnam but now I use e-mail all the time and I feel much happier.

When this group of Vietnamese people understood that self-management programmes would not replace Medicare-funded services, they were enthusiastic that the programme would be available in their own language and run by people who, like themselves had a chronic illness. They offered to promote it among their community groups and to assist in recruiting participants.

Greek focus group

Participants in this group had serious chronic illnesses and multiple co-morbidities. They all felt that their illnesses had caused them severe limitations and created dependency on family and friends. Dependency had a strong association with social isolation.

Participants saw social isolation as a strong factor in remaining ill and not gaining control over one's life. The participants who were successful in gaining some control achieved this by looking outwards from their families, to social clubs, volunteering and new activities such as reading.

> I got sick after my husband died. After three years I started to pull myself together – my grandchildren were always asking me to cook for them and I started there. Then I began to eat again and I started going out to the clubs to be social. I also read a lot of books when I am alone at night.

Another theme to emerge was that the participants saw themselves as having little control over their health. Some participants said they had anticipated developing diabetes. Alternatively, participants said they never expected to become ill because they had led very healthy lives or in one case that it was God given. Other reasons for becoming ill such as the environment, stressful life situations and loneliness, compounded this view that control over health eluded them. Additionally, those who had explored strategies to assist themselves found they were of limited value. Hydrotherapy helped one person cope with her arthritis but exacerbated her asthma. Massage helped another person temporarily. Lack of success compounded feelings of no control over external influences.

> The environment is bad, we are lonely – that's why we get ill.

The group saw self-management in terms of its potential to address their social isolation. For example, one woman considered that it was important to make action plans, as there was no one to help her. However, because they were isolated, a self-management programme should provide information about their medical situations. Other aspects of the self-management programmes such as dealing with depression through positive self-talk were easily understood and very helpful. Primarily, the group saw such a programme as addressing their needs by giving them an opportunity to socialize with others in like-circumstances.

Where peer leaders were concerned, participants identified people with chronic illnesses in their immediate community they considered would make good peer leaders. The concept of volunteerism was strong in this group as was the view that people who had suffered setbacks could assist others. This assisted them to see peer leadership in a positive light.

Italian focus group

The elderly Italian participants of this focus group viewed their illnesses as contributing to physical weakness. They described themselves as weak, 'flat', 'wobbly' or 'shaky' with arthritis, cardiovascular problems or diabetes, so that it was no longer possible to garden or walk. Illness limited their activities.

There was a strong view that weakness and illness were an inevitable part of ageing. One man said that 'people were like cars – something was bound to happen'.

At the same time, the participants were self-reliant. They tried to manage without medication or by using home remedies, such as ice packs. Other strategies included going to the pharmacy for advice. One man who had had a heart attack said that the extremity of this incident had caused him to 'run' to the doctor. Although their doctors informed them of the range of allied health services they were less likely to use them because of the expense involved.

They felt comfortable with the concept of self-management. As all of the participants in this focus group were involved in a social club they saw self-management programmes as a means to provide more isolated elderly Italians with strategies and information to help them cope with health problems.

Action plans were not conceptually alien to Italians. Participants said plans encouraged people to participate in their own care.

Related concepts such as self-talk were easily recognized as cognitive strategies that assist people to reinforce positive behaviours. A discussion of the advantages of distraction to deal with pain and discomfort that might lead to depression fostered a discussion among the participants of previous experiences with depression. These experiences were associated with life circumstances, such as the death of a spouse and living alone. The participants used techniques of distraction to deal with sleeplessness or anxiety.

Peer leadership was not fully discussed in this group. The participants who were involved in social groups for elderly Italians suggested they would make competent peer leaders.

Discussion

The major finding from these focus groups was that there were far fewer changes to be made to the programme to make it relevant to each cultural group than was predicted by ethnic health professionals. This is another example of how there is often considerable disparity between health professionals' perceptions of patients' health beliefs and expectations, and patients' actual beliefs and expectations. This has been demonstrated in the areas of prescribing,[25,26] enquiries about lifestyle issues such as smoking and alcohol consumption [27–31] and willingness to be told about the diagnosis of cancer.[32–36] All the participants, regardless of their cultural background understood the concepts associated with self-management programmes.

While there was some dissent in the Chinese focus group over the value of peer leaders, the discussion that took place around the issues demonstrated that, nevertheless participants understood the reasons for using them. On the whole, all participants in the focus groups were excited by the idea of peer leaders who spoke their own languages. Peer modelling is an important component of the CDSMP. The importance of modelling and its relationship to improved health outcomes has been suggested by the theoretical work of Bandura[37] on self-efficacy and has been demonstrated in several self-management programmes.[38] The findings of this study demonstrated that self-management programmes taught by laypersons could achieve similar results compared with those achieved by professionals, with peer-led self-management programmes sharing many characteristics with professionally led programmes: (i) they are both evidence based; (ii) they have both demonstrated measurable effects in terms of outcomes; and (iii) they both include medical management of conditions. How peer-led self-management programme differ, however, is that they (i) are driven by the patient rather than the health professional; (ii) facilitate and promote patient efforts to manage chronic illness using the theory of self-efficacy; and (iii) they are cost-effective.[38,39]

The focus groups produced new understandings for the researchers, which assist in the modification of the programmes and potential benefits to these communities. First, participants from each community had different responses to their illnesses. The Italian people saw their illnesses in terms of weakening bodies related to ageing, while Greek people saw their illnesses as caused by their increasing social isolation and the stresses associated with caring for others. Chinese people related their physical health to a harmoniousness. Vietnamese people viewed their health in relation to their displacement from Vietnam and its culture.

These responses reflected differing social circumstances and differing emotions. The Vietnamese participants often expressed anxiety, largely because they did not understand why they were ill, and did not have all the information they would like. For some Vietnamese, this meant they would feel more comfortable in Vietnam where they understood the health system. Others felt more confident about the Australian health system, although language was a barrier for complete access. Participants in the Greek focus groups expressed depression and anger. Both emotions were strongly related to life circumstances, such as grown children being too busy to care for them or a life of manual labour. Poor health was a result of such circumstances. The Chinese participants' responses suggested that health could be influenced by state of mind, regardless of the outside circumstances and social conditions, although the better these were, the easier it was to 'have a light heart'. The Italian focus group participants had experienced depression over their failing strengths, but this had been overcome by becoming more socially active and substituting activities.

This suggests that these emotional responses may not be solely 'ethnic', that is, a culturally based response to health. A large part of the response relates to existing circumstances such as the length of time in Australia and their position in the life cycle.

Fatalism was not a central issue in the participants' responses to health. No one considered they had no influence on their health. Having a sense of control in life circumstances emerged as an important factor for all the participants.

Most of the participants were aware of times when they experienced a loss of control. For the Vietnamese focus group this was strongly associated with the onset of illness and the inability to understand their health care. For the Greek group loss of control was associated with an inability to influence changing life circumstances. Those who came closest to being fatalistic were the Italian focus group members who saw their loss of control in terms of ageing. However, they adopted compensatory behaviour. Participants who had experienced depression and worked their way out of it always suggested that part of their success in this area was that they had consciously adopted a strategy to assist them cope better. Similarly, Vietnamese people actively adopted physical exercise as a means to assert their control. In all cases those who had undertaken to make themselves feel better had gained more control over their lives, were less depressed and expressed enjoyment in their lives despite their health.

Proficiency in English across all the focus groups was variable. Greek and Italians tended to switch between their native language and English, but required explanations of complex concepts in their own languages. At the end of each focus group, participants were asked to read and sign a receipt for payment of an honorarium. It became apparent that there was a high level of illiteracy amongst all participants in both English and their native language. Such a finding supports those of the Australian Bureau of Statistics (1996) literacy report. CALD people may experience considerable difficulties in using many of the printed health resources, something that needs to be considered when implementing self-management programmes with people from CALD backgrounds.

Conclusion

The focus groups confirmed that the concept of self-management and the strategies related to it, such as cognitive symptom management, are compatible with the experiences of people with chronic illnesses from a range of cultural backgrounds.

They offered an insight into how people from different cultural backgrounds view their health in relation to the rest of their lives, as well as dispelling myths about the centrality of fatalism and reliance on expertise. However the differing responses by each group suggests that people from different cultural backgrounds will connect with different aspects of the same self-management programme. At present there has been little research into what elements of the programme are most effective and relevant for people from non-English speaking cohorts. Further research is needed in this area to identify the elements of the Chronic Disease Self-Management Programme from which participants benefit the most. These focus groups provided the building blocks, providing some insight into the elements which may be of more relevance to people from non-English speaking cohorts.

Despite the need for further research into the programme elements, the results of the focus groups enabled modifications to the programme in order to make it accessible and equitable to people from non-English speaking backgrounds. The major modifications concern the need to provide interpreters at times when consent and data collection are required and not to rely on information written in either English or the participants' native languages. Another important modification is the adaptation of the book that accompanies the programme. This resource is only available in English, at present. In order to provide accessible resources for all people from these communities it will require either the book to be translated or a script to be developed from the book and be audio-taped.

Four focus groups do not provide exhaustive information about culture and health in relation to the concept of self-management programmes. They are merely a starting point from which to begin to design programmes that are relevant and contribute towards improving health outcomes for a significant proportion of the Victorian population.

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