

Self-management of chronic conditions: implications for rural physicians of a demonstration project Down Under

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This article has been peer reviewed.

Objectives: This paper describes the outcomes achieved for clients of a demonstration project in self-management in one of Australia's most rural and remote states.
Methods: Client survey data obtained over a maximum of 18 months from 264 clients in 3 sites across Tasmania were analyzed using standard descriptive techniques. These data provided demographic information as well as client self-assessments of health and well-being, and health-related behaviours. Tests of significance were conducted on differences in client health data over a maximum of 4 data collection times.
Results: In relation to demographic factors, these data show low education, employment and income levels in an aged population. There were gender differences in project participation (many more females than males), and relatively low levels of completion of the self-management course by those who were not married and who were living with their families. Statistically significant improvements in health dimensions were obtained for those clients attending the self-management course (where p values < 0.05): in the areas of distress, symptoms and depression. Data also show significant declines over time in client ratings of exercise behaviours and cognitive self-management strategies.
Conclusions: The effects of barriers to self-management of chronic conditions (lack of formal education, age-related physical frailty, and poverty) are likely to be multiplied in areas showing a paucity of health professionals and related health infrastructure. The data for gender and living arrangements suggest the importance of tailoring self-management programs to meet the needs of specific community sub-groups. Declining ratings are one of the least explored areas of self-management research, yet they point to the importance of sustaining interventions in rural communities. Rural physicians apprised of the issues in implementing successful self-management programs in rural contexts can be an important resource for more isolated communities wanting to achieve workable programs with sustainable gains.

Objectifs : Cet article décrit les résultats produits pour les clients par un projet témoin d'autogestion dans l'un des États les plus ruraux et les plus éloignés de l'Australie.
Méthodes : On a analysé des données de sondage réunies, pendant une période maximale de 18 mois, auprès de 264 clients à 3 endroits en Tasmanie en utilisant des techniques descriptives normalisées. Ces données ont produit de l'information géographique ainsi que des autoévaluations par les clients de leur état de santé et de mieux-être et de leurs comportements reliés à la santé. On a soumis à des tests d'hypothèse les différences au niveau des données sur la santé des clients pendant un maximum de quatre périodes de collecte de données.
Résultats : En ce qui concerne les facteurs démographiques, ces données indiquent de faibles niveaux d'éducation, d'emploi et de revenu dans une population âgée. Il y avait des différences entre les sexes au niveau de la participation au projet (beaucoup plus de femmes que d'hommes) et les taux d'achèvement du cours d'autogestion chez les célibataires vivant avec leur famille étaient relativement faibles. On a obtenu des

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améliorations statistiquement significatives des dimensions de la santé chez les clients qui ont suivi le cours d'autogestion (où la valeur $p < 0,05$) au niveau de la détresse, des symptômes et de la dépression. Les données montrent aussi des reculs importants avec le temps des cotes obtenues par le client pour les comportements d'exercice et les stratégies d'autogestion cognitive.

Conclusions : Les effets des obstacles à l'autogestion de problèmes chroniques (manque d'éducation structurée, fragilité physique reliée à l'âge et pauvreté) sont susceptibles d'être multipliés dans les régions où les professionnels de la santé et l'infrastructure connexe de la santé sont rares. Les données sur les sexes et les conditions de logement indiquent qu'il importe de personnaliser les programmes d'autogestion de façon à répondre aux besoins de sous-groupes particuliers de la communauté. Les évaluations à la baisse constituent l'un des aspects les moins étudiés de la recherche sur l'autogestion, mais elles révèlent qu'il importe de maintenir les interventions dans les communautés rurales. Les médecins ruraux informés des problèmes posés par la mise en œuvre de programmes réussis d'autogestion en milieu rural peuvent constituer une ressource importante pour les communautés plus isolées désireuses d'implanter des programmes pratiques qui produiront des gains durables.

Introduction

Patients with one or more chronic conditions are a significant portion of clients seen by physicians. Appropriate interventions for these clients are a major concern for physicians, particularly in rural areas where distance and isolation can multiply the effects of having too few support professionals and a health infrastructure that may not meet the needs of the rural residents.

The broad concept of self-management has been applied to the management of chronic conditions. These include symptom action plans, client diaries, and care-planning for chronic conditions such as asthma and diabetes, and cognitive and behavioural treatments for chronic low back pain.[1–6] The results of different styles of chronic disease self-management programs in Australia, including for indigenous Australians, suggest a basis for cautious optimism. However, there is a generally acknowledged need to become clearer about what strategies might be most appropriate for particular sub-groups, such as rural communities.[6] The efficacy of specific self-management interventions in rural areas or, more broadly, the opportunities and challenges that rural areas present for the ethos of self-management in health service delivery, remains relatively unexplored.

Previous studies have demonstrated a range of results for the Standard Questionnaire for Chronic Disease Self-Management 2000 course (the Stanford course), a 6-week self-management program for people with chronic conditions.[7,8] The aim of self-management in this context is to improve the health of clients by helping them become active partners with their care providers. The focus is upon modifying client behaviours using an education program based on the idea that clients with chronic conditions share common challenges.[9,10] Ideally, the Stanford course is delivered by trained laypersons in keeping with its emphasis on the persuasive power of community role models. It can be described as a generic, interactive group program where pairs of trained facilitators use structured manuals to deliver a course emphasizing self-efficacy through guided feedback sessions, problem-solving, goal-setting and making action plans. During the 6-week program, role modelling, reinforcement, group learning and symptom re-interpretation occur.[11,12]

Self-management appears to be underpinned by social learning and behavioural theories, associated initially with Albert Bandura,[13] which emphasize an individual's abilities as an active learner in social contexts. Self-management approaches commonly involve helping an individual mobilize cognitive and behavioural capacities in goal-directed ways in the interests of improving health status and reducing health service use.

In Australia, self-management has had particular public policy appeal in a political climate that emphasizes personal responsibility and, at the level of health service delivery, the development of participative and client-centred styles of health care services. Similar cultural changes in Canadian health services have been observed over the last 2 decades, exemplified in the 1986 WHO document, *Ottawa Charter for Health Promotion* (www.who.int/health promotion/conferences/en/).[14]

This paper describes the outcomes achieved for

clients of a demonstration project in self-management in one of Australia's most rural and remote states. It also offers some implications for medical practitioners in rural areas wanting to know more about the benefits and contra-indications of self-management programs, including the Stanford course.

Methods

The Tasmanian demonstration project was funded by the Australian Government's Department of Health and Aging, as 1 of 8 demonstration projects for its Sharing Health Care Initiative across Australia. It ran from June 2001 to June 2004 under the auspices of the University Department of Rural Health, University of Tasmania.

Study sites

Tasmania is a temperate island off the coast of south-eastern Australia with over 40% of its unique wilderness areas protected in national parks and other reserves. The almost 500 000 people who live on Tasmania are relatively older and are more decentralized than in mainland Australia. This has brought numerous challenges: Tasmanians have lower incomes, higher rates of unemployment, and lower education participation rates than other Australians.[15] All of Tasmania outside the capital city of Hobart is variously classified as "rural" according to the Rural, Remote and Metropolitan Areas classification system used by the Australian government in policy and funding decisions, which is based on low population density and distance to large population centres.[16] However, the size (population 199 000) and isolation of Hobart in the state's south give it many of the characteristics of a large regional centre.

The study used 3 sites on Tasmania: the Break O'Day Municipality on the northeast Tasmanian coast, which has a scattered population of 5553 with 47.3% over the age of 45; the Devonport region on the north-central coast, which has a population of 45 175 with 39.5% of the population over 45; the Glenorchy municipal area, which is located in the southeastern part of the state on the outskirts of Hobart and has a population of 42 447 with 38.29% over 45.[17] In each of these sites the project was administered from a central office: in Break O'Day and in Devonport the offices were in community heath services centres and in Glenorchy the site office was situated in Glenview Homes, which is an elderly care residential setting. The first 2 sites could be described as rural and regional, and the third site (Glenorchy) is essentially remote metropolitan. These terms — "rural," "regional" and "remote metropolitan" — capture the different natures of the study sites, which were in a country area, a country town area, and a small city serving surrounding country areas.

The survey

The survey instrument was developed by the project's National Evaluators, PriceWaterhouseCoopers in consultation with the local evaluators for each individual project. The team examined a wide range of available quality-of-life instruments before settling on a design that combined a number of these.

At the heart of the instrument are self-management evaluation tools developed by the Stanford Patient Education Center (http://patienteducation.stanford.edu/research/index.html), with some modifications to adapt it to Australian cultural differences and local project design. The instrument included a number of questions covering client demographics constructed from items drawn from the Australian Bureau of Statistics, 2001, Australian Household Census.[17] Other sections were drawn from: The Satisfaction with Life Scale, developed by the Center for Outcome Measurement in Brain Injury (www.tbims.org/combi/bg.html) and the Kessler Psychological Distress Scale developed by the School of Survey Research Center of the Institute for Social Research, University of Michigan.[18] In addition, the Tasmanian project included a number of survey and interview questions developed locally, and the Partners in Health Scale, developed by the Flinders University Coordinated Care Training Unit.[14]

In summary, the client information component was designed to collect data to do with client characteristics, situation and chronic conditions. The client health component was designed to collect data about clients' assessments of general health, distress levels, symptoms, exercise levels, health strategies (mostly cognitive), disability levels, intrusiveness of the condition (or multiple conditions) in daily life, self-efficacy and confidence in one's own coping abilities, depression and life-satisfaction.

The client service use component of the survey was designed to obtain client assessments of frequency of use of health services (but not hospital inpatient or emergency department visits), as well as use of community services, and self-help/support groups.

The study offered self-assessment data for 4 different time points for clients participating in self-management programs over an 18-month period, as well as those who simply enrolled in the project but did not go on to participate in those programs.

Study sample

Site officers recruited clients for the program and for the surveys using a range of methods (contact with local community groups, letters, telephone calls). This method of recruitment meant that clients who self-identified as having at least 1 chronic condition (of any kind) were included in the study. Clients with chronic conditions were recruited into the self-management project between August 2002 and September 2003: clients entered and left the project at different times. All clients recruited for the project were surveyed at least once (at baseline). Subsequent surveys depended on client willingness to respond to follow-up invitations from site staff:

Clients were formally enrolled in the project and were offered opportunities to participate in a range of programs helpful to self-management of their chronic conditions. At the centre of these programs was the Stanford course (unmodified), although the project included a myriad of other programs and workshops delivered by community and health service organizations: programs to do with exercise, cooking for diabetes, Internet use and computer skills, managing grief, falls prevention, pain management, use of medicine, as well as workshops on specific conditions such as osteoarthritis and osteoporosis.

Our data do not show clients who had attended other courses but not the Stanford course.

Statistical analysis

As the observational data set for this demonstration study was discontinuous and not based on a random sample, the emphasis of the analyses was upon using different approaches to complement and supplement each other. Our analysis used summary statistics such as means and standard deviations (SDs), and also boxplots to show distributions around a median, as well as paired sample t tests. Changes in self-assessments of health over time were explored (where p values < 0.05) for groups identified by survey participation (long-term or up to 18 months, v. short-term or up to 6 months), as well as course participation (this involved 2 main groups, those who had done Stanford and other courses, and those who had done no courses).

Boxplots give an indication of effect size, while t tests give some indications of significance — a statistically significant but small effect size has less interesting implications for practice.

The study was approved by the University of Tasmania's Human Research Ethics Committee.

Results

A total of 264 clients were enrolled in the project. Eighty-eight (33.3%) clients were from Break O'Day; 61 (23.1%) were from Devonport; 115 (43.6%) of clients were from Glenorchy. There were many more females (198 [75%]) than males (66 [25%]). The median birth year ranged from around 1930 to 1940 across all 3 sites. Most clients (82.6%) were Australian or born in England, although 26 (9.8%) were Polish-born. Only 1.9% of these clients were employed full-time: most clients (233 [88.3%]) were supported by a government pension.

Over one-third of respondents indicated they had a post-secondary school qualification of some kind — much lower than in the Tasmanian population where 52.2% of people have such qualifications, which in turn is much lower than the general Australian population, where the figure is 67.7%.[19] Approximately half of the clients (52.3%) were married or de facto. Most clients (70.5%) did not have a caregiver; only 16.7% of clients had a live-in caregiver. Arthritis was by far the most common condition (212 [80.3%] clients), followed by cardiovascular disease (174 [65.9%]), depression (88 [33.3%]), and chronic respiratory/lung conditions (81 [30.7%]), diabetes (56 [21.2%]), osteoporosis (46 [17.4%]), renal disease (25 [9.5%]). "Other conditions" were also indicated by 128 (48.5%) clients.

Twenty-nine clients were surveyed only at baseline, 81 were surveyed only at baseline and 6 months after baseline; 110 were surveyed only at baseline, 6 months and 12 months; and 44 clients were surveyed at all 4 data collection points.

Fifty-nine health service providers and 15 peer leaders were trained to deliver the Stanford course. A total of 26 Stanford courses were delivered to 204 clients.

The survey also contained a group of questions about course participation. This identified 3 groups: clients who had attended the Stanford course only (15 [5.7%] clients), clients who had attended Stanford and other courses (189 [71.6%]) and clients who had enrolled in the project but not attended

any course. Our data do not show clients who hadn't taken the Stanford course but who had taken other courses.

For 148 of the 204 clients who had attended the Stanford course, duration of attendance in weeks was obtained. This showed that only 65 (43.9%) of respondents to that question completed the full 6 weeks of the course.

Data analysis

The data analyses were based on 2 major groups of data: those to do with client characteristics and those to do with changes over time in client health.

As noted, many more women than men enrolled in the project — 198 (75%) and 66 (25%) respectively; 81% of enrolled women and 69% of enrolled men went on to do the Stanford course. Those men who did go on to take the Stanford course were more likely to complete the 6-week course (a median attendance of 5 wk out of a possible 6) than women (a median attendance of 3 wk).

In relation to course participation, living arrangements and marital status, the largest group (104 [40%]) was married people, living with family, who had done the Stanford course and other courses. The next largest group (49 [18.6%]) was widowed people living alone who had done the Stanford course. The other 111 clients were scattered across 26 different permutations of

- course participation (just the Stanford course, the Stanford course and other courses, or no formal courses but enrolled in the project);
- marital status (never married, widowed, divorced, separated, married); and
- living arrangements (living alone, with family, with others).

Married people living with family were the highest completers of the Stanford course, with a median participation of 4 weeks. In contrast, the median participation in the Stanford course of the widowed group living alone was less than 2 weeks.

It has already been noted that surveyed clients had a wide range of chronic conditions. However, clients with arthritis tended to have higher completion rates for the Stanford course (a median of 4 wk), whereas the medians for all the other groups of clients with chronic conditions were 2 or fewer weeks. That is, our data on completion of the Stanford course are heavily affected by the presence of a large number (118) of highly motivated clients with arthritis and other joint/bone conditions.

The presentation of the findings that follows should be read with the following in mind. The *p* value relates to the 2-tailed test of the *difference* between the mean change for one group and the mean change of the other group. The null hypothesis that is being rejected is that the difference for the 2 groups is zero.

We report the following in relation to changes over time in client assessments of health.

- General health: There was an initial improvement from baseline to 6 months for clients observed over the long-term, particularly in the data for clients who did no courses (significant 2-tailed 0.012). Overall mean and SD at baseline were 3.340 and 1.201; overall mean and SD at 6 months were 3.095 and 1.286).

- Distress: There was an improvement (or decrease in distress) for clients surveyed over the short term, most noticeably those who took the Stanford course and no other course, but also those who took the Stanford course and other courses (sig. 2-tailed 0.007). Overall mean and SD at baseline were 2.607 and 1.160; overall mean and SD at 6 months were 2.445 and 1.

- Symptoms: There was a improvement from baseline to 6 months and from baseline to 18 months for those who had done the Stanford course and another course, or only the Stanford course (sig. 2-tailed 0.001 and 0.045). Overall mean and SD at baseline were 4.331 and 2.150; overall mean and SD at 18 months were 3.651 and 1.786.

- Exercise: There was a decrease in exercise from baseline to 6 months as reported by clients surveyed over the short term. These were primarily the group that had not taken any course, but it also included those who had done the Stanford course and no other course (sig. 2-tailed 0.043). Overall mean and SD at baseline were 1.804 and 0.552; overall mean and SD at 6 months were 1.748 and 0.503.

- Cognitive health strategies: There was a decrease in the use of health strategies over the long term, most noticeably those who had not done any courses, but also between 6 months and 18 months for those who had done the

Stanford course and other courses (sig. 2-tailed 0.008 and 0.025). Overall mean and SD at baseline were 2.545 and 1.238; overall mean and SD at 18 months were 2.192 and 0.880.

- Depression: There was an improvement from baseline to 6 months observable for clients who did at least the Stanford course (whether only the Stanford course or the Stanford course and other courses) (sig. 2-tailed 0.012). Overall mean and SD at baseline were 4.035 and 0.717; overall mean and SD at 6 months were 4.122 and 0.702.

There were no significant changes as far as disability, intrusiveness of the condition, self efficacy, or life satisfaction. No changes were observed in the data for client service use, nor were any changes observed in the data for use of community services, or attendance at self-help groups.

Discussion

Random treatment/control studies have an important role in delivering evidence-based accounts of such interventions as the Stanford course. However, observational studies of rural communities may add value by translating the experiences of rural communities in ways that point to gaps in the existing research.

The Tasmanian data (showing education levels, ages of clients, living situations, employment situation and income sources) suggest the extent of barriers — lack of education, age-related physical frailty, and poverty — that clients might experience in trying to manage their chronic conditions. The effects of these barriers are most likely multiplied in underserviced areas.

Our data suggest that self-management programs may well work differently for different groups. For example, the data on enrolments by gender suggest that recruitment strategies that work for one gender may not work for another. The data on living arrangements and course completion suggest that some groups, such as those living alone, may require particular support to complete self-management courses. The contrasting efficacy of self-management education programs such as the Stanford course for particular groups, and the nature of particular barriers to self-management at work in rural and remote areas, are some areas that need more exploration.

Although there are several areas of apparent improvement (feelings of distress, symptoms, depression), we were particularly interested in self-ratings that worsened over time, noting the relative lack of exploration of such effects in self-management research in general. Our data seem to raise the question whether some dimensions of health and well-being (such as cognitive health strategies taught by the Stanford course) were more vulnerable to "early gains" and "late losses," i.e., an improvement or at least a maintaining of baseline levels followed by a decline or a return to baseline such that the client is no better off (and sometimes worse off) than before the intervention began. We wondered whether in rural and remote areas with reduced health services and community infrastructure, this effect may be more pronounced. The mere presence and, equally, the cessation of an intervention in a rural area where clients have few such opportunities might well produce greater effects in outcome data. Certainly, the anecdotal evidence we have from working with these communities indicates they believe themselves to be "better off" with no interventions than with poorly sustained interventions, particularly of the political "here today, gone tomorrow" kind.

"No improvement" and "declining" effects as such have been observed in evaluations of the effectiveness of Stanford self-management programs in the area of disability, for example.[11,20] Their implications for particular populations such as rural and remote communities have scarcely been explored. The general lack of hypotheses about effect sizes adopted in advance in random treatment/control studies of self-management programs makes it difficult to tell the difference between a decline that is actually a positive effect of the program (it could have been worse) and a decline that indicates the program is not working as it should for a particular population. There is a need in future research for upfront quantitative indications of the expected magnitude of deterioration over time, incorporated into multivariate models, so that we can see if the observed deterioration is more or less than what was expected.

It is also possible that some dimensions of health are particularly resistant to intervention and may get worse almost in response to intervention.

What are the implications of these data for rural physicians in other countries, such as Canada? In rural and remote areas physicians may well play a key role in directing or advising their communities about the kinds of self-management programs that are needed. They may also have a range of opportu-

nities to advise about the appropriate approaches to self-management for their communities at the state and national policy levels. Certainly, once such programs are implemented in their local communities, rural physicians may be approached for their assistance, for example, by way of making advertising material available in their clinics or by participating in evaluations of their effectiveness.

Our experience suggests rural health contexts present particular challenges for self-management education programs. It is not that they do not work so well in rural areas, but that they may not work so well when transplanted to rural and remote communities without careful attention to specific barriers to self-management in those communities.

Our data suggest that these programs need to target particular groups and the barriers that exist in their recruitment and participation. Rural physicians are well placed to provide advice that can help identify these groups and their needs in the local community. In this way rural physicians might have a key role to play in ensuring that self-management education programs work optimally for those most in need in their communities, rather than groups already relatively well placed to benefit from self-management programs.

Our data also suggest that this targeting of groups needs to account for the lower education levels and greater poverty of some rural, regional and remote metropolitan communities. While self-management education programs such as the Stanford program are certainly not based on a "one size fits all" assumption, it seems that the extent of tailor-making that these courses require if they are to meet the needs of special sub-groups, is something physicians can emphasize in their local communities. Further, it is likely that factors such as access to transport and costs play a role in high attrition rates obtained for attendance at the Stanford course in Tasmania. Making self-management programs work in rural, regional and remote contexts is about thinking through those access barriers.

Our data also carry the implication that sustainability of gains is a major issue in the success of self-management programs. Rural physicians can emphasize to their communities that such programs also need to be implemented with an eye on the future sustainability of their gains, with a significant community capacity building component, if they do not want to run the risk of leaving rural, regional and remote communities worse off (or no better off) than they were before. This building of community capacity, while a key feature of our project, was a crucial and particularly difficult part of making self-management work on our island.

Limitations

This study has a number of limitations arising from the size of our data set and the difficulties we experienced gaining data from clients over the full 18-month period. As a community demonstration project it was not experimentally controlled, our sample was not random and our results are not generalizable.

When clients completed the Stanford course our data were heavily affected by 118 highly motivated clients suffering from arthritis and other joint/bone conditions.

Our data do not show clients who had attended other courses but not the Stanford course, an important point since the amorphous concept of self-management might reasonably include a range of learning opportunities clients might have had but did not tell us about.

As a study of client self-assessments, our data are unable to provide insight into changes in client health observed by health practitioners, including physicians. However, the results obtained have clinical and practical relevance, across similar cultural contexts where the same challenges can be found.

Conclusion

The Tasmanian data suggest some of the challenges of self-management education programs in rural and remote areas. Yet they also suggest the potential for tailored, strategic interventions that are responsive to particular community needs, and target particular community groups. A key orientation of effective self-management programs should be sustainability. Physicians in rural communities can have some confidence that if the experiences of other rural and remote communities are heeded, their clients should benefit from the presence of self-management education programs.

Acknowledgements: The project was funded under the Australian Government Department of Health and Ageing's Sharing Health Care Initiative. It involved collaboration between the University Department of Rural Health, Tasmania, the State Department of Health and Human Services, Arthritis Tasmania, and Glenview Homes Inc. Thanks are owed to site and project staff for collecting and entering the data used in this analysis.

Competing interests: None declared.

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