

'Just for us ladies': intersections of gender, education, economic status and other factors affecting the success of self-management in rural contexts

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OVERVIEW

"He thought it was just for us ladies" is how one client in rural Tasmania described her husband's decision not to attend the Stanford Chronic Disease Self-management course ('the Stanford Course') offered by our demonstration project. Thinking about that client's decision led to the central question of this paper: "How do gender, education, economic situation, cultural and other factors intersect to affect the success of self-management programs in rural and regional settings?"

Exploring this question and its practical implications involves bringing together methodological issues in handling multi-variate data, with international data about self-management using the Stanford course, and the experience of handling a small, non-randomised dataset obtained as part of the evaluation of the Commonwealth Sharing Health Care initiative in Tasmania.

The task of obtaining useful information from the small, non random sample datasets typically obtained from rural settings is no easy one. This paper explores whether and how these kinds of datasets might provide important directions for policy and practice, as well as future research.

The Sharing Health Care initiative in Tasmania seems to invite such exploration because of its breadth and diversity: clients with a range of chronic diseases in three very different sites across Tasmania (not only rural, but also remote metropolitan), and a project with an overall goal of improving self-management of these clients over a two year period. In particular, the methodological challenges presented by the client surveys conducted as part of the evaluation help pose such questions as: Does consideration of multiple factors in evaluation data have a particular role to play in getting richer information from rural programs? Can multi-variate data analyses help us better reach clients obscured by more simplistic data analyses – those who are most isolated, most vulnerable, most needing help in rural communities? How can the answers to such questions help use make better in-practice decisions about self-management and other programs in rural communities?

This paper explores such questions in three parts:

- some statistical and methodological issues in self-management studies
- some statistical and methodological lessons from a Tasmanian demonstration project in self-management
- implications of these for practice.

PART ONE: SOME STATISTICAL AND METHODOLOGICAL ISSUES IN SELF-MANAGEMENT STUDIES

The methodological context of self-management studies

Over the last decade or so, there has been considerable research (mostly American) into the benefits of certain styles of self-management for chronic conditions (mostly for asthma, but also diabetes, and arthritis) that present clients with multiple long-term life challenges and consume substantial health care resources.^[1-5] In particular, some success has been demonstrated for the Chronic Disease Self-Management Program (the 'Stanford course'), a six week program for those with chronic conditions associated with Dr Kate Lorig of the Stanford Patient Education Center.^[6,7] This course aims to assist clients with chronic conditions become proactive partners in their own health care, utilising cognitive and behavioural capacities to improve health and reduce health service use.^[8-10] It grew out of arthritic self-management programs, and an evidence-based emphasis upon lay trainers and positive role modelling, as well as peer support for arthritis self-management.^[11-14] It can be described as a highly interactive, group-based generic program facilitated by pairs of trained leaders using highly structured manuals. Bandura's notion of self-efficacy is central: the Stanford program emphasises the development of self-efficacy through guided feedback sessions, problem-solving, setting goals, and making action plans, during which role modelling, reinforcement, observing and learning from each other and reinterpreting signs and symptoms occurs.^[14-16] The intention of the program is that it serve heterogenous communities.^[17]

Reports of the success of self-management courses, including those for the Stanford course, typically focus upon changes in health status, and desirable cognitive and behavioural changes, as well as service use (and do include multi-variate data analyses such as multiple regression).^[5,12-14,18] An emerging literature in this area shows that the benefits of self-management programs such as the Stanford course (compared with no intervention) include outcomes related to constructs such as pain, disability, health distress, self efficacy, exercise, as well as particular health care services utilisation.^[5,14,15,18] Such studies focus on comparing an intervention group with a control group in randomised trials.

Key statistical and methodological issues presented by the self-management literature

At its simplest level, the data from the Tasmanian study, like many other studies of self-management, were obtained by client surveys that produced self-reported data.

Client surveys can, of course, be analysed one question at a time or a single response (for example, reported pain) can be taken to be the dependent variable, the one predicted from all the other questions. Once we seek to handle several responses at once (what is the impact of a treatment on reported pain and exercise levels taking into account age, gender and other illnesses), we are involved in some form of multi-variate analysis.¹

The challenges presented to the analyst by this sort of client survey are considerable. The synthesis of statistical issues that follows is drawn from the work of some key statistical texts that I have used to highlight method issues most relevant to the Stanford literature.^[19-21]

¹ This term has a narrower meaning to some writers, who would see a distinction between multiple regression (one dependent variable, multiple predictors) and multivariate analysis such as principal component analysis, discriminant analysis and the like). Others make a distinction between univariate regression (one predictor) and multivariate regression. In this paper, we use the term multivariate to cover the situations where we seek to take into account lots of variables at once.

First, the voluntary nature of participation means that any statistical inferences, even where participants are allocated randomly to different treatment groups, generalise only as far as the population of persons who are prepared to participate. Allowing for the voluntary nature of participation is difficult. We can get some indications of the match of demographic characteristics (age, gender, education) with the base rural population from data published by the ABS, and we may be able to find such data for the segment of the rural population with such conditions from health statistics.

Secondly, as noted, much of the data is self-reported. There is no clear reason to assume that errors in self-reporting are independent of, unrelated to, gender, age, economic and cultural factors – let alone the severity of any illness. We should not bury this issue under a statistical mantra of “assuming essentially uncorrelated errors”. Of course, if not built in to the design of the study, it is not possible to do much more than to be open to the possibility that the dataset includes some clear pointers to powerful hypotheses but they are masked unless we can identify them. The use of, for example, multiple regression² “controlling” for gender and other factors is one way to seek to do this but has some important limitations. In randomised trial studies, (participants allocated at random to treatment and control groups), controlling³ for gender and age lets us identify, in principle, the effectiveness of the treatment even if the errors in self-reporting are such that older females report on average less change in pain than younger males. How we do this analysis, however, is not just a matter of plugging the data into some canned statistical routines, since we have choices to make that depend on some underlying models or hypotheses about the causes at work – females experienced the same gain but reported it as less or males experienced a smaller gain but reported it as more.

Thirdly, when we fit a model, especially a multi-variate one, to the data we cannot just report summary statistics such as R^2 or p-values. We must

- look at the data to see that it seems to have the distributional characteristics needed by the model
- look at the residuals (the difference between the data and the modelled data) to see that the residuals are not trying to tell us that something doesn't make sense.

For example, the ages of participants (older persons with serious medical conditions) are likely not to have the sorts of distributions where it is appropriate to use means and standard deviations – although, as in the use of t-tests, this seems to be expected practice. It is also often important in choosing our model to take into account that some variables are like weight and height, some like degrees centigrade and some are categories.

Fourthly, all participants do not stay to the end. And they are likely to do so in systematic ways, ways related to the factors we are trying to study. Good design builds in from the outset some ways of following up non-respondents and drop-outs to get some idea how our conclusions might have been affected had we heard from everybody. The effect of missing data can be dramatic: not only can our estimates of effects be over or under the mark (the real effect is much smaller or much larger) but they can, under certain conditions, be completely in the wrong direction.

² Where participants are in groups – different rural centres, for example – mixed effects modelling [(or hierarchical linear regression) is increasingly preferred to simple multiple regression (see Pinheiro 2000). The challenge for rural health is that our datasets are often too small and too sparse for us to be able to estimate more than a handful of parameters.

³ There are two different uses of the idea of a control: a control group, the one that doesn't get the treatment in question (possibly nothing or possibly some other treatment) and controlling for the interaction of, say, gender and tendency to report levels of pain.

Fifthly, when the data are collected at multiple time points, linear models may incorrectly report the changes. Linear models are often a good starting point, of course, but not always (the speed of a falling object over the first few seconds is adequately fitted by the sort of linear model often used to analyse surveys).

What does all this mean for self-management studies in rural contexts? To begin to explore the answers to this question we will now turn to lessons from our Tasmanian study.

PART TWO: SOME STATISTICAL AND METHODOLOGICAL LESSONS FROM A TASMANIAN DEMONSTRATION PROJECT IN SELF-MANAGEMENT

Overview of the Tasmanian study

The Tasmanian demonstration project that is the point of departure for this paper was funded by the Australian Government's Department of Health and Ageing, as one of eight such projects under the banner of the Sharing Health Care Initiative. The project was implemented by the University Department of Rural Health, Tasmania, from June 2001 to June 2004. It involved 264 enrolled clients participating in different kinds of self-management programs: the Stanford course, as well as life skills and exercise programs, self-management workshops on falls prevention, pain management, and medicine use, and education sessions on particular conditions such as osteoarthritis and osteoporosis. Only 44 clients completed surveys for all possible four time points over the eighteen months of the data collection. The study was conducted on three sites across Tasmania: the Break O'Day Municipality on the north-east Tasmanian coast; the Devonport region on the north-central coast; the Glenorchy municipal area in the south-east of the state in the northern suburbs of Hobart.

The survey instrument used had three parts: part one obtained client information and was administered at baseline only; part two obtained client health information and was administered a baseline, six, twelve, and eighteen months; part three obtained health services use information and was also administered at all data collection points. The survey itself was developed by the project's national evaluators, PriceWaterhouseCoopers, consulting with the local evaluators. The content of the survey was drawn from

- demographic questions constructed from the Australian Bureau of Statistics 2001 Australian Household Census
- the Stanford Questionnaire for Chronic Disease Self-Management (slightly modified for Australian conditions)
- the Satisfaction with Life Scale developed by the Center for Outcome Measurement in Brain Injury (<<http://www.tbims.org/combi/bg.html>)
- the Kessler Psychological Distress Scale developed by the School of Survey Research Center of the Institute for Social Research, University of Michigan
- the Partners in Health Scale developed by the Flinders University Coordinated Care Training Unit
- some other questions developed locally in Tasmania (these included questions about course participation).

The findings of the analyses of the client surveys conducted for the Tasmanian study have been presented in a paper that will be published in a forthcoming issue of the Canadian Journal of Rural Medicine. However, rather than offering the detail of those findings, this paper focuses upon the methodological lessons the project offers for self-management programs, particularly in rural areas – lessons for participation and outcomes.

Participation

Recruitment

We do not know (except anecdotally) how the use of recruitment strategies in our study, however broad, worked to select out particular clients. We also do not have reliable information about the profile of chronic conditions of those in our rural areas (at least). Nor were we able to find any Stanford evaluations that matched recruitment strategies to demographic and other client data. The high proportions of clients with arthritis we attracted (212 or 80.3% of clients) is likely to be an artefact of our recruitment strategies (such as the effects of efforts by particular community interest groups – Arthritis Tasmania was very involved in the project).

Further, in line with the Stanford and broader self-management literature^[17], our data show that many more males than females participated (a ratio of 1:3). Does the marketing of such self-management courses effectively engage with culturally engrained attitudes (such as emotional self-sufficiency) held by older males in rural areas?

We also know very little about the characteristics of those males that do respond to the recruitment strategies used by self-management programs such as ours. We do not know whether, for example, males with certain characteristics (education, occupation, socio economic well-being, marital status and living arrangements) are more responsive to particular recruitment strategies. In our study, those males who did enrol were in fact better completers of Stanford than females (a median attendance of five weeks as opposed to three weeks). This highlights the possibility that while males might not be as likely as females to attend self-management courses, as signalled by Stanford studies^[18], the populations of males and females attracted to self-management courses might be more similar in terms of responsiveness to programs.

Our Tasmanian clients also tended to have much lower levels of education than the general Tasmanian population, which in turn has much lower levels than the general Australian population. Education is in fact a variable of interest in the Stanford data, separating out completers and non completers.^[18] However, what we do not know is how education levels might interact with other factors to affect recruitment.

It may be that engaging with rural communities' responses to self-management requires us to develop new demographic markers, or rework existing ones. It may be that 'education level' does not tell a story as rich as a variable that is about predisposition: for example, whether a person has a habit of attending local TAFE and other courses unrelated to self-management of the chronic condition.

Completion

Another interesting opportunity for multi-variate data analysis comes from consideration of the completion rates for particular conditions – our arthritis clients were much better completers. It is unlikely that the populations of clients with different chronic conditions are equal in terms of the combination of factors influencing completion. If health conditions are related to a complex array of socio-economic and other variables, it seems likely that the

different populations of clients with different conditions are not equally positioned to complete self-management courses.

Our study also provided indicative information that living arrangements and marital status (being married and living with family versus being widowed and living alone) might be a door into understanding completion rates. We found that median completion rates of the widowed group living alone were much lower (less than two weeks) than married people living with families (4 weeks). This is of interest in a context where the Stanford literature refers to dropout rates but does not really explore the range of possible factors and their relationships that might be affecting completion.^[10,18]

Outcomes

There were ten key constructs in our self-reported data on perceived health status: general health, distress, symptoms, exercise, cognitive strategies, disability, intrusiveness of condition, self-efficacy, depression, and life satisfaction.

Positive changes over time

What does it mean to say an area possibly relevant to health – the clinical significance of some of these constructs is unknown in our population at least – has ‘improved’ over time?

Our study provides findings that echo, in part, what has been observed in the self-management studies cited earlier – there are improvements in several health constructs. We found improvements over time in the areas of (perceived) distress, symptoms, and depression among those who had participated in self-management courses, including the Stanford course. Such changes over time in the different health constructs in the self-management literature really need to be understood in terms of multiple variables that show, for example, particular configurations of disadvantage working in different rural contexts.

Improvements then a worsening of ratings over time

The Stanford self-management literature does not really engage with the phenomenon observed in our data, of health-related dimensions that show an improvement then a worsening over time. What can explain the effect of an intervention when the data are showing that participants are worse off by, say, eighteen months than they were at baseline? We observed such effects in, for example, our data on cognitive strategies. It seems likely that these effects are the result of a complex set of interacting factors, but which ones? We know even less about whether particular rural areas are more or less likely to show these effects, though people in rural communities often tell us that interventions can leave them worse off than before if they are not sustained.

Exploring such events in self-management data involves a focus on alternative models and on possible confounding⁴ factors, which we may be able to allow for with stratification (looking at each subset separately) or multi-variate models.

No changes in ratings

In the light of expectations that clients with chronic conditions will get worse over time, the Stanford literature points to the presence of data showing no change as possibly positive.^[18] Our data suggest apparently static dimensions in, for example, disability and self-efficacy.

⁴ A confounding factor occurs when the change in something we are interested in is linked with some other (possibly unidentified) factor. Confounding factors can cause our results to be partially wrong (right direction but wrong size and significance) or completely wrong (wrong direction and wrong significance).

This takes us into the idea of being explicit about the underlying hypothesis when we apply statistical tests. For example, a p-value on the difference in mean reported pain is a statistical value of a test seeking to reject the null hypothesis that we expect *no* difference in reported pain over time. If we have good upfront reasons for expecting, in the absence of any intervention, pain to get *worse* over time then we have used the wrong null hypothesis. Of course, the randomised treatment/control study is one way to handle this but it is also clear that future research into Stanford should include exploration of such upfront hypotheses. Expectations about the constructs associated with the Stanford course are still unclear.

Worsening ratings over time

The presence of worsening ratings over time on particular health dimensions is a feature of this and other self-management studies, such as disability ratings in at least one Stanford program evaluation.^[18] In our study we found this to be so in the case of, for example, exercise. But how can we tell the difference between a worsening over time that is a positive effect of the program (it could have been even worse) and one that suggests the program is not working as it should in a particular area?

Clearly, randomised treatment/control studies are a good way to handle this but may not be definitive. If we accept *a priori* the notion that the program does in general have a positive value then the presence of worsening ratings over time can be thought of as indicative of the presence of some confounding variable that is obscuring the results and we can seek to identify its presence and assess its impact.⁵ Again, any upfront quantitative indications of the expected magnitude of deterioration over time can be incorporated into the model so that it is possible to see if the observed deterioration is more or less than the expected.⁶

PART THREE: IMPLICATIONS FOR PRACTICE

This discussion has highlighted what we don't know about self-management in rural contexts. Knowing what we don't know can also be a powerful tool for practice:

- policy decision makers can examine the detail of self-management programs, to ensure that they are designed to move understandings forward for rural communities
- health practitioners can work closely with those delivering self-management programs to help ensure they are 'tailormade' for their communities
- diverse community groups can support more vulnerable and less well-resourced clients to 'stick with' and obtain value from self-management programs
- clients can help shape new variables that will tell the story of self-management in their community
- course designers can better translate the findings of multi-variate studies into the design features of courses.
- evaluators can use hypotheses as drivers of the design of instruments such as surveys, and as guides to the task of knowing what to test in the data.

⁵ Although it is important to be cautious : a paper by Freedman (1983) demonstrates that with the "right" screening techniques it is possible to find models that create systematic effects from random data.

⁶ It is not possible to over-estimate the scientific importance of obtaining (and writing down) such estimates right at the start of the study, *before any data are collected*.

CONCLUSIONS

While random treatment/control studies have an important role in delivering evidence-based accounts of programs such as self-management, they do not necessarily work automatically to intuit new hypotheses and research variables that can engage with the local and particular circumstances of rural communities. Non random sample studies often deliver apparently messy and inconclusive evidence, but it is precisely this feature than can make us think through the various factors that may be at work and which multi-variate data analyses can help us explore. This paper has examined what some of the gaps and silence might be in the emerging literature on self-management, and how one small demonstration study offers a basis for developing better approaches to understanding who succeeds and why in these programs, particularly in rural contexts.

ACKNOWLEDGMENTS

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 the local evaluator Dr Peter Orpin, site staff (Samantha Tiernan, Ella Ashley, Rowena Leitch, Maggie Koerbin, Nicki Fletcher and Julie Milne) for collecting the data for these client surveys, and to Sarah D'Arcy for her data entry work.

Helen Cameron-Tucker, Coordinator of Physiotherapy and Cardiopulmonary Rehabilitation Services, and Master Trainer for the Stanford course, at the Department of Physiotherapy, Royal Hobart Hospital, Tasmania, provided valuable comments on this paper.

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