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Determining the Efficacy of the Chronic Disease Self-Management Programme and Readability of “Living a Healthy Life with Chronic Conditions” in a New Zealand Setting

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Abstract

**Background**: Self-management programmes are an increasingly popular way of treating chronic diseases.

**Aims**: This study aims to determine the efficacy of the Stanford Chronic Disease Self Management Programme (CDSMP) in a New Zealand context, by assessing course outcomes and readability of the accompanying reference guide, “Living a Healthy Life with Chronic Conditions, 4th Edition”

**Methods**: This is a cross-sectional pre-post study conducted in Auckland between August 2009 and September 2015, using CDSMP participants’ baseline and follow-up Health Education Intervention Questionnaire (heiQ™) data. Readability of the guide was assessed using Gunning Fog Index, Coleman Liau, Flesch Reading Ease, Flesch Kincaid Grade Level and SMOG scores.

**Results**: Significant evidence of improvement ($p \leq 0.001$) was observed in seven of the eight domains measured by the heiQ™. Greatest improvements were seen in skill and technique acquisition (mean change score 0.25, $p \leq 0.001$) and self-monitoring and insight (0.18, $p \leq 0.001$). There was little evidence of improvement in health service navigation (0.04, $p=0.17$). Readability analyses indicate that a person needs to be reading at a minimum of U.S. 8th grade level in order to understand the text, and possibly up to 11th grade.

**Conclusions**: The CDSMP is effective for improving patient self-efficacy in the New Zealand setting. However, adaption of the program to support better health service navigation is warranted. The readability of the reference guide is not suitable for this setting and requires further improvement.
**Keywords:** Chronic disease, self management, self efficacy, heiQ™, readability

**Introduction**

Chronic diseases are rapidly increasing globally, contributing to significant morbidity and mortality rates, causing a large burden on healthcare resources. In response to this growing predicament is a rising popularity of self-management courses. One of the most popular versions is the Stanford Chronic Disease Self-Management Programme (CDSMP), developed by Stanford University. The Chronic Disease Self-Management Program is a 6-week, small-group intervention attended by people with different chronic conditions. It is taught largely by peer instructors from a highly structured manual. The program is based on self-efficacy theory and emphasizes problem solving, decision making, and confidence building. The primary intended outcome is to improve participant health behaviour, self-efficacy (confidence in ability to deal with health problems), health status, and health care utilization, assessed by self-administered questionnaires. The programme aims to provide individuals with the skills and knowledge to confidently and effectively manage their condition.

There is an abundance of both randomised controlled trials (RCTs) and longitudinal studies on the efficacy of the CDSMP, most of which have been overwhelmingly positive. Of these RCTs the chronic conditions participants suffered included depression, type-2 diabetes, heart disease, stroke, or participants were from rural or lower socio-economic backgrounds. The literature on the efficacy of the CDSMP...
have reported reduced fatigue, pain, healthcare costs, improved medication adherence, healthcare service utilisation, health behaviour and quality of life. However, a large proportion of the relevant literature is associated with the programme developers, leading to potential bias. There is also possible negative publication bias, whereby studies showing nil effect have not been published. Nevertheless, it is a fact that the vast majority of studies have been conducted in the United States and United Kingdom. Thus, we believe it is important to assess its efficacy in the New Zealand setting.

In New Zealand, primary health organisation ProCare has been contracted by the local district health boards as a provider of these programmes in the Auckland region. These programmes have been run by ProCare since 2008. The CDSMP involves attending 2.5 hour sessions at a community location, every week for 6 weeks. The programme is led by trained health professionals or peer or lay-person (members of the community trained for the role, rather than health professionals). To ensure reliability of consistent programme content, leaders are instructed to strictly adhere to the provided programme manual. Benefits of using laypeople as leaders are increased relatability for patients, as well as the decreased financial cost of employing health professionals, often compounded by a shortage of health professionals.

The programme attempts to achieve its aims through strategies such as weekly action planning, skills mastery (e.g. mindfulness, decision making), role modelling (by facilitators and peers), and peer persuasion. It also tries to increase participant knowledge. Often forgotten is the important role of the social support provided by regular meetings. Participants are encouraged to exchange
contact details and engage outside of weekly meetings, as well as staying in touch after the course ends.

Aside from the aforementioned, another key aspect of the CDSMP is a participant reference guide, “Living a Healthy Life with Chronic Conditions, 4th Edition”\(^8\). During sessions, leaders direct participants to specific sections that are relevant to the session content. Participants are encouraged to read it during the week to extend and reinforce their knowledge beyond the basics covered during the session. However, there are concerns about the user-friendliness of this guide. These concerns are due to the (perhaps) excessive length of the guide at 343 pages, the amount and complexity of text, and the sparsity of non-text components. It is important to remember that these programmes are targeted to the high needs population, and thus the guide needs to be comprehensible and accessible to people with significant health literacy barriers.

Methods:

Participants

All patients attending South Auckland, ProCare CDSMP sessions were asked to complete a baseline Health Education Impact Questionnaire (heiQ\(^\text{TM}\)) at the first and last session, six weeks apart. Responses from August 2009 to September 2015 were included in this study. Participants to the Procare CDSMP either self-refer after reviewing advertisements in local libraries, community venues, newspapers or practice waiting rooms, or are referred by their GP or nurse. The referral criteria include those over 18 yrs old with long term health condition or carer/family member of someone with a long term health condition. Self-referral is usually by phone call or
Referral from general practice is by fax or electronic referral system. Total number of referrals that do not result in attendance to the Procare CDSMP is not captured in this audit. Underlying medical condition of the participant was not recorded. For the purposes of characterising the group, we have data on a small, random subset of the group (n=76) for which ethnicity and age is presented. If the participant was also seeing a Procare registered medical professional at the time of the self-management programme, clinical data was collected. Unfortunately that only 4-6 participants fall into this category.

**Questionnaires**

The Health Education Impact Questionnaire (heiQ™) allows for the evaluation of the effects of education interventions provided to patients with chronic diseases. The heiQ™ is a validated psychometric tool designed for reliable evaluation of self-management and/or health education programs, widely used throughout the world. It covers eight domains: (1) positive and active engagement in life, (2) health directed behaviour, (3) skill and technique acquisition, (4) constructive attitudes and approaches, (5) self-monitoring and insight, (6) health service navigation, (7) social integration and support, and (8) emotional wellbeing and negative affect. Each domain is assessed by between four and six questions, with forty questions in total. Responses are marked on a four-point Likert scale, using the endpoints “strongly disagree/strongly agree”. A higher score indicates better self-efficacy, except in the emotional wellbeing and negative affect domain which is negatively scored.

*heiQ™ data extraction*
The domain score for each section of the heiQ™ was calculated as the mean of the responses to the individual questions comprising the domain. Some questionnaires were incomplete. For incomplete questionnaires, the domain score was calculated as the mean of the completed items. If no questions for a specific domain were answered, mean substitution was utilised to generate a domain score (i.e. the sample mean domain score was used as the participant’s domain score). 25 domain scores over 16 participants were calculated using this substitution method. Mean change scores for each domain were calculated so that positive scores reflect an improvement in self-efficacy. Thus, for domains (1) to (7), mean change score = sample mean follow-up score - sample mean baseline score. However, as domain (8) is negatively scored, mean change score = sample mean baseline score - sample mean follow-up score.

heiQ™ data analysis

Statistical analysis was undertaken using SPSS. A paired t-test was used to compare the pre- and post- intervention heiQ™ scores for each domain and used to generate confidence intervals for mean change scores.

Effect sizes (ES) were calculated for each domain by dividing the mean change score by the sample standard deviation of the baseline domain scores. The effect size was calculated to support the interpretation of the magnitude of the outcomes, beyond significance or otherwise. Using Cohens effect size interpretation, an ES of <0.2 is small, an ES of 0.2-0.8 is moderate, and an ES of >0.8 is large.10

Readability
The CDSMP incorporates the use of a key participant reference guide. The reference guide is 343 pages long and written by authoritative experts in the field. In order to give a representative sample of the entire book, readability analysis was conducted on one page from each of the nineteen chapters. The fifth page of each chapter was selected (or last full page of the chapter in one case, due to chapter fourteen being only four pages in length). This was to avoid the introductory passages at the beginning of each chapter, which may have resulted in underestimation of readability scores. Individual scores for each chapter were then averaged to yield mean readability scores for the entire reference guide, and standard deviations for the mean generated using Microsoft Excel.

We determined the readability using Gunning Fog Index, Coleman Liau, Flesch Reading Ease, Flesch Kincaid Grade Level and SMOG scores. This was achieved by inputting the text of each excerpt into a publicly accessible web-based tool. A brief description and the formula used to generate each scores are provided below and in Table 1.

The Gunning Fog Index assesses readability and describes it in a reading grade level, representing how many years of formal education is required for comprehension of a passage\(^{11}\) In contrast, the Coleman Liau index focuses on the number of letters in words \(^{Error! Bookmark not defined.}\). The Flesch Reading Ease (FRE) score is widely used by the U.S. government \(^{12}\), and derives a reading level for a given document. The FRE produces a score between 0 (very difficult to read) and 100 (very easy to read). The is a modification of the FRE, the Flesch Kincaid Grade level (F-K) also allows readability to be described in terms of a reading grade level \(^{11}\). Finally the Simplified
measure of gobbledygook (SMOG) determines a reading grade level and is commonly
used in analysis of health literature\textsuperscript{11}. Multiply scores were calculated as any one
score has limitations.

\textit{Insert Table 1 here.}

\textit{Plain language checklist}

To complement the readability analysis, an additional analysis using a “Plain
Language Checklist”\textsuperscript{13} was undertaken. The checklist contains 60 criteria, of which
58 were applicable to the participant reference guide. The criteria are grouped into
categories of vocabulary, sentences, paragraphs, organisation, tone, inclusive
language and accessible resources, design concept, font, typeface, space, colour and
finish, and graphics.

\textbf{Results}

\textit{Participants}

We had ethnicity and age data on a subset of the population, of the 76 participants, 23
were Maori, 23 were NZ European, 3 were Samoan, 3 were Cook Island (other), 3
were European, 2 were Indian and 2 were Pakistan. The remainder did not specify
ethnicity. The average age of the subset was 52 yrs, with a standard deviation of 15
yrs, as not all participants recorded their age, or had their age entered electronically
into the Procare database. Procare staff (author FA) involved with the self-
management programme have stated this is reflective of the population that
participate in CDSMP (unpublished data). An unpaired t-test showed no evidence for
differences in baseline scores between participants that completed the course, and those that did not.

Response rates

In total, 471 baseline and 317 follow-up heiQs were completed. Only patients who had completed both baseline and follow-up heiQs were included in the analysis (n=273). Excluded data was a factor of participants not completing the programme (i.e. attending less than 4 sessions, n=198), or starting at a later session (n=44). Data on those invited to participate, but didn’t, was not captured.

Questionnaires

For each domain, at least 30% of patients had an improved follow-up score compared to their baseline scores. Only 11 patients (4%) did not show an improvement in at least one domain. The heiQ™ results are summarised in Table 2 below. Using Cohen’s effect sizes, our analysis suggested the CDSMP has a moderate effect on all domains except health service navigation, for which a small effect is suggested.

Insert Table 2 here

Figure 1 shows the mean change score and confidence interval for each domain. For all domains except health service utilisation, there was significant evidence that domain scores differed between baseline and follow-up heiQs. For health service utilisation, there was no evidence that baseline and follow-up domain scores differed.

Insert Figure 1 here

Readability
Using the Gunning Fog Index, the mean readability score for the entire reference guide was 10.32 years (SD=2.49), indicating over 10 years of formal education is required for a person to easily understand the text. The mean readability score calculated using the Coleman Liau Index was 9.30 (SD=2.10), using the F-K grade level was 8.76 (SD=2.11), and using the SMOG grade level was 10.79 (SD=1.81). These results indicate that a person needs to be reading at a minimum of U.S. 8th grade level in order to understand the text, and possibly up to 11th grade. The mean FRE score was 57.31 (SD), indicating it is fairly difficult to read and can be considered easily understood only by those above the 9th grade\textsuperscript{14}.

**Plain language checklist**

The participant reference guide met 47 of the 58 applicable criteria. It scored most highly in the organisation, tone, colour and finish, and graphics categories, meeting 92-100\% of the criteria in these categories. Important criteria that were not met were “use of simple, familiar words that reflect the intended audience’s common language”, keeping all sentences and paragraphs short, providing alternative accessible formats (such as large print, Braille, audiotape, electronic versions), reasonable length overall, sufficient white space around text blocks, and simplicity of tables/charts.

**Clinical outcomes**

Participants for which clinical data was collected (n=6) is presented in Figure 2. Whilst results for blood pressure and HbA1c look promising the sample size is too small to make conclusions.

*Insert Figure 2.*
Discussion

This study is the first investigation into the efficacy of the CDSMP in New Zealand. Our results suggest that the CDSMP appears to be effective in those that complete the programme. While the CDSMP has been widely used in many countries, most of the efficacy research has conducted in the United States and United Kingdom. Furthermore, the developers of the program have been involved in a large proportion of the existing published research, leading to potential conflicts of interest.

The heiQ™ is a questionnaire specifically designed to assess an education intervention for those with chronic conditions. It has been assessed for validity both in Australia and in Germany, where factorial elements were examined in about 1200 rehabilitation patients with a variety of chronic conditions\(^\text{15}\). Although using a sample that included different chronic conditions, this study suggested remarkably stable psychometric properties of the heiQ™ over time\(^\text{15}\).

Our results suggest the CDSMP was effective in improving self-management behaviours, as shown by the heiQ™ results. Health service navigation was the only domain that did not definitively show an improvement; all other domains had some degree of effect. To elaborate, the health services navigation domain measures the understanding and ability of an individual to interact with health organisations and professionals, and the ability to have their health requirements met by the healthcare system. To improve the effect on the health navigation domain, we recommend incorporating more information and skills regarding navigating the
New Zealand health system, and raising awareness of relevant publicly accessible resources. Given the programme was developed overseas and that facilitators are recommended to stick closely to the material, we recommend further adaptation to educate about the New Zealand health service system – similar to what has already been done to incorporate New Zealand nutrition guidelines into the manual.

The heiQ™ is a validated tool for assessing the effect of self-management programmes. A limitation of the questionnaire is the four point scale, as it may not have sufficient sensitivity to detect smaller effects. Conversely, it could also cause overestimation of effects, as a 1 point change in score (the smallest change possible in the questionnaire) indicates a 25% improvement. Fortunately, the data presented in this research is the culmination of grouped data.

While attendance of the CDSMP is associated with improvements in self-efficacy, it is also possible that the benefits have arisen from the supportive social environment of attending group sessions (i.e. perhaps the actual content of the course has little beneficial effect). Social support is widely accepted as being a strong indicator of both physical and psychological health and is crucial for patients living with chronic diseases. It is also important to consider other possible confounding factors – such as participation in other care planning or case management programmes that may have caused the change scores we observed.

An area of concern is participants that have worsened scores following the CDSMP – depending on domain, this ranges from 18% to 34% of participants (Table 2). Further investigation is required to determine whether the CDSMP is contributory to this and
if so, develop screening methods to identify those likely to worsen and prescribe an alternative intervention for these individuals. Further studies should also control for possible confounders.

As previously mentioned, the accompanying participant reference guide is a key component of the programme. It is designed to facilitate patients to explore concepts taught in the sessions in more depth and provide support outside of sessions. However, due to its length and wordiness, we had concerns about its readability and approachability. Following our investigation, the readability scores proved our concerns correct. The scores indicated that a reading grade of at least U.S. 8th grade is required, and possibly up to 11th grade.

The recommended reading level for health education information varies greatly between sources. Multiple authorities (including the U.S. National Institutes of Health, American Medical Association, U.S. National Cancer Institute and American Medical Center Cancer Research Group) recommend that a reading level of 4th-6th grade is ideal for comprehension of health education materials.17 As literacy levels in New Zealand are similar to the United States,18 these same recommendations should apply for health education programs in New Zealand also. Overall, the New Zealand population has poor health literacy16 with skills also varying greatly between ethnicities – this is important due to New Zealand’s multi-cultural composition. Māori have significantly poorer health literacy than non-Māori, with four out of five Māori males and three out of four Māori females having poor health literacy.18 Also, Pacific Islanders and other ethnic minority groups also have higher levels of poor literacy than the general population.18 We recommend future studies
should also investigate the health literacy of the participants attending CDSMP sessions in order to gain more insight into the suitability of the reference guide.

Furthermore, there was large inter-chapter variability in readability, as indicated by the large standard deviations. We believe this may be due to chapters being written by different authors, as the guide has six authors in total. This is important as while some chapters were deemed comprehensible at a 5th or 6th grade level, others ranged up to a 12th grade level, or even up to 2nd or 3rd year university levels. We suggest that the guide is revised in the next edition to improve the overall readability and consistency between chapters.

Additionally, readability formulae are frequently criticised due to their focus on number of words per sentence, or the number of letters or syllables per word. They do not take into account the comprehensibility of sentences or the vocabulary that is being used, which is particularly relevant when assessing health education information.12, 14, 20 Nor do they consider the overall length of each passage or the entire text itself. They also do not consider the layout, presence/absence of graphics, logical flow or crucially, the ability to invoke interest in the reader.12, 14, 20, 21 However, as long as we do not forget the limitations of the formulae, they can still be helpful.

The plain language checklist allowed a more holistic assessment of the reference guide. The checklist identified the need to use simpler and more familiar words that are common in the everyday language of our target audience, providing alternative formats (electronic versions are particularly welcomed in this digital era), shortening
of the overall length, and simplifying some of the tables in the guide. The use of more diagrams or illustrations may also aid with improving its ability to interest and engage the reader. The plain language checklist also assesses the overall presentation of the document including graphics and pictures, of which the CDSMP manual rates well.

**Conclusion**

The results of this study suggest that CDSMP is beneficial for improving self-efficacy of chronic disease patients. Further studies assessing outcomes over a longer period of follow up, in addition to studies on the effects on clinical outcomes are recommended. Improvements to the reference guide may also increase the effectiveness of the CDSMP.

**Acknowledgements**

The authors thank ProCare for providing access to the participant questionnaires and reference guide, and the University of Auckland for funding the audit.
Figure 1: Mean change scores and 95% Confidence Interval for each HeiQ™ domain (p-values for all mean domain change scores is ≤0.001, except domain 6, p=0.17).
Figure 2: Individual change pre to post self-management intervention for Weight (kg) (A), HbA1c (B), Systolic blood pressure (C) and Diastolic blood pressure (D)
**Table 1: Readability scores, formula and abbreviations**

<table>
<thead>
<tr>
<th>Readability Test</th>
<th>Formula</th>
<th>Abbreviations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gunning Fog Index</td>
<td>0.4 (sl + %lw)</td>
<td>sl = average number of words per sentence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>%lw = percentage of words with three syllables or more</td>
</tr>
<tr>
<td>Coleman Liau Index</td>
<td>(0.0588 L) - (0.296 S)</td>
<td>L = average number of letters per 100 words</td>
</tr>
<tr>
<td></td>
<td></td>
<td>S = average number of sentences per 100 words</td>
</tr>
<tr>
<td></td>
<td>15.8</td>
<td></td>
</tr>
<tr>
<td>Flesch Reading Ease</td>
<td>206.835 - 0.846 wl - 1.015 sl</td>
<td>wl = average word length in syllables</td>
</tr>
<tr>
<td></td>
<td></td>
<td>sl = average sentence length in words</td>
</tr>
<tr>
<td>Flesch Kincaid Grade</td>
<td>0.39 sl + 11.8 spw - 15.59 sl</td>
<td>sl = average sentence length in words</td>
</tr>
<tr>
<td></td>
<td></td>
<td>spw = average number of syllables per word</td>
</tr>
<tr>
<td>Simplified measure</td>
<td>3 + √(lw30)</td>
<td>lw30 = the number of words with three syllables or more per 30 sentences</td>
</tr>
<tr>
<td>(SMOG)</td>
<td></td>
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Table 2: Summary of HeiQ™ outcomes for each domain

<table>
<thead>
<tr>
<th>HeiQ™ domain</th>
<th>N improved (%)</th>
<th>N no change (%)</th>
<th>N worsened (%)</th>
<th>Mean change score effect size</th>
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</thead>
<tbody>
<tr>
<td>1. Positive engagement with life</td>
<td>144 (53)</td>
<td>57 (21)</td>
<td>72 (26)</td>
<td>0.36</td>
</tr>
<tr>
<td>2. Health directed behaviour</td>
<td>152 (56)</td>
<td>51 (19)</td>
<td>70 (25)</td>
<td>0.28</td>
</tr>
<tr>
<td>3. Skill and technique acquisition</td>
<td>149 (55)</td>
<td>75 (27)</td>
<td>49 (18)</td>
<td>0.50</td>
</tr>
<tr>
<td>4. Constructive attitudes and</td>
<td>136 (50)</td>
<td>62 (23)</td>
<td>75 (27)</td>
<td>0.24</td>
</tr>
<tr>
<td>approaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Self-monitoring and insight</td>
<td>154 (56)</td>
<td>51 (19)</td>
<td>68 (25)</td>
<td>0.41</td>
</tr>
<tr>
<td>6. Health service navigation</td>
<td>105 (38)</td>
<td>91 (33)</td>
<td>77 (28)</td>
<td>0.08</td>
</tr>
<tr>
<td>7. Social integration and support</td>
<td>125 (46)</td>
<td>60 (22)</td>
<td>88 (32)</td>
<td>0.20</td>
</tr>
<tr>
<td>8. Emotional well-being and</td>
<td>146 (53)</td>
<td>33 (12)</td>
<td>94 (34)</td>
<td>0.21</td>
</tr>
<tr>
<td>negative affect</td>
<td></td>
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