# Self-management in chronic conditions: partners in health scale instrument validation

Isabel Peñarrieta-de Córdova and colleagues describe the validation of a tool to evaluate self-management of chronic disease and explore the findings of the patient evaluation itself

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## Abstract

**Aims** This article describes a study that aimed to validate the Self-care in Chronic Conditions Partners in Health Scale instrument in the Mexican population. The instrument has been validated in Australia for use as a screening tool by primary healthcare professionals to assess the self-care skills and abilities of people with a chronic illness.

**Methods** Validation was conducted using baseline data for 552 people with diabetes, hypertension and cancer aged 18 or older who were users of healthcare centres in Tampico, Tamaulipas, Mexico.

**Results** Results show high reliability and validity of the instrument and three themes were identified: knowledge, adherence, and dealing with and managing side effects.

**Conclusion** The findings suggest the scale is useful as a generic self-rated clinical tool for assessing self-management in a range of chronic conditions, and provides an outcome measure for comparing populations and change in patient self-management knowledge and behaviour. The authors recommend validating the scale in other Latin-American settings with more research into the effect of gender on self-management.

**Keywords**
Chronic illness, self-care tool, self-management

DISEASES SUCH as diabetes, cancer and hypertension are among the most prevalent chronic health problems in the world. They represent the most common causes of disability and consume the most health expenditure globally (World Health Organization (WHO) 2009, Holman and Lorig 2000, Harvey *et al* 2008).

This is particularly true in countries such as Mexico, where non-communicable disease accounts for 78% of deaths and the leading causes of death are diabetes mellitus, ischaemic heart disease and cerebrovascular disease. The northern states of the country have higher prevalence, including Tamaulipas (Sistema Nacional de Información en Salud 2012, Instituto Nacional de Salud Pública de Mexico (INSP) 2012).

Despite the huge amount of resources allocated to diabetes and hypertension management in Mexico, evidence suggests this has made little difference because too few patients receive treatment (Córdova-Villalobos *et al* 2008). The increasing prevalence of, and mortality from, diabetes and ischaemic heart disease, the high cost of care and poor outcomes from care strategies have led to the development of specialty outpatient units for chronic diseases.

The main objective of these units is to prevent and treat the most prevalent non-communicable diseases using an innovative model to ensure comprehensive and interdisciplinary care of patients and, consequently, help reduce hospital congestion and operating costs.

The first units were launched in 2007, and by late 2011 there were 83 in 29 of the 32 states in Mexico. Evaluation in 2012 of the impact of the units, however, revealed there is still much to do. For example, 35% of the patients interviewed had to buy their own drugs because of shortages in the unit, and 25% did not get their full prescription in their last medical consultation. Local mechanisms of referral and counter-referral of patients, as well as communication pathways, also need to be reviewed to ensure adequate continuity of care for patients arriving at medical units. Staff training also requires improvement (INSP 2012).

The evaluation also revealed that in some states the number of units has decreased, despite the high demand for hospital services and increase in the prevalence of chronic conditions and associated complications. This is a concern for Mexico in general and for the state of Tamaulipas in particular, which has some of the highest numbers of patients with long-term conditions (Sáenz-Salinas 2010). The decline in the number of units suggests that chronic conditions are poorly self-managed, which is supported by studies into self-care among, for example, people with diabetes (Avila-Alpirez *et al* 2006, Amador-Díaz *et al* 2007, Compeán Ortiz *et al* 2010, Alarcón Luna *et al* 2012).

The decrease in the number of these outpatient units is a negative indicator of care to support users of these units, reflecting that this proposal still needs to be improved to create spaces that enhance self-management for people living with a chronic illness.

To manage this increasing burden, it is vital to understand how to improve patients' self-management. One way of doing this is to use an instrument that objectively assesses patients' knowledge and self-management behaviours, and evaluate the effectiveness of educational interventions that promote self-management of long-term conditions.

## Self-management

The concept of self-management has been defined in various ways. Barlow *et al* (2002) defined it as a person's ability to manage the symptoms and consequences of living with a chronic disease, including treatment, physical, social and lifestyle changes. Lorig and Holman (2003) point out that even if a person does not have a chronic disease, they are still responsible for managing their own health but, for those with a chronic illness, self-management is a lifelong task. They identify the goal of self-management as keeping well, psychologically and physically.

To do this, people with a chronic disease have three tasks, originally described by Corbin and Strauss (1988):

- To manage medical aspects of the disease.
- To manage roles in life, including changes in the roles caused by the disease, for example having to change the pace of work or to stop working.
- To manage the psychological consequences of chronic disease.

To perform these tasks, people need the following basic self-management skills: problem solving, decision making, access to resources, the ability to build partnerships with healthcare providers, and the ability to take action (Lorig and Holman 2003).

Various chronic disease self-management programmes have been developed based on these concepts. Among the most-mentioned and with its effectiveness proved is the Flinders Program (Lorig *et al* 2001, Lawn *et al* 2009). Based on the above review of the definitions of self-management, the study described in this article validated the Flinders Program in the Mexican context, to evaluate behaviours in chronic disease self-management (Battersby *et al* 2003, Petkov *et al* 2010).

The programme is a care-planning process developed at Flinders University in Adelaide, South Australia to involve patients in a partnership with health and social care professionals to manage their chronic diseases effectively. It defines self-management as avoiding unnecessary complications, maximising quality of life, and maximising informal and formal support from, for example, community social networks and healthcare providers.

For people to be involved actively in their care, they must understand their condition, the effect it has on their lives and how to manage this; good communication between patients and healthcare providers, and among healthcare providers, is also essential. The Flinders Program is based on six principles for effective self-management (Lawn *et al* 2009) (Box 1, page 34).

The Partners in Health (PIH) scale was developed by Flinders University to evaluate self-management behaviour in health centres. It consists of 12 questions (Box 2, page 34) for the patient with a chronic condition to complete that measure four aspects of self-care (Battersby *et al* 2003, Petkov *et al* 2010):

- Adherence to treatment.
- Knowledge of the disease.
- Management of side effects.
- Management of signs and symptoms.

The PIH scale measures the main components of self-management in a number of chronic diseases

**Box 1 Six principles of effective self-management**

**Patients should:**

- Know about their condition.
- Follow care plans agreed with their healthcare providers.
- Share in decision-making, know how to self-manage, have plans and goals that they regard as important, be willing and able to achieve at least some self-management training and have access to at least some support services.
- Monitor and manage signs and symptoms of their condition, be proactive and sustain follow-up rather than waiting for new problems to occur.
- Manage the effects of their condition on their physical, emotional, and social lives.
- Adopt lifestyles that promote health.

and is designed for use by primary care providers and their patients. Patients answer each question on a Likert scale from 0-8, where 0 is 'very little', 'never' or 'not very well', and 8 is 'a lot', 'always' or 'very well'. This article reports the results of validation of the instrument in a bi-national project between Peru and Mexico, conducted to strengthen self-management and family care in chronic diseases in primary care.

## The study

The objective of the study was to validate the PIH scale among users of primary care in a Mexican context. The study sample consisted of 552 randomly recruited adult patients with diabetes, hypertension and cancer registered at health centres in Tampico, Tamaulipas or at the outpatient clinic of the local hospital.

Nursing students from the Tampico faculty of nursing at the University of Tamaulipas who were trained to use the scale carried out the survey, supported by members of the clinical teaching faculty who monitored implementation. The training enabled students to understand the instrument's questions and to ensure it was applied consistently. The supervisors were trained to verify correct application of the instrument.

The instrument measures patients' skills and abilities across a range of self-management categories or domains represented by the 12 questions, and the scoring process tracks this over time. The approach served to highlight areas where patients require further education and information.

The validation was conducted in two phases. First, a translator who specialises in technical healthcare translated the instrument into Spanish, and then back into English to ensure that the translation was accurate. Subsequently, the instrument was piloted on a population similar to the study sample, consisting of 30 people, to analyse understanding of each of the 12 questions. As a result, some terms were adjusted without changing the meaning of the question. Second, construct validity of the instrument was tested.

The validation of the instrument was performed with two objectives: to analyse if the themes regarding self-management identified by the authors of the instrument was adjusted to the context of the Mexican population, applying a statistical technique called exploratory factor analysis; and to verify if the questions of the instrument were consistent, that is repeatable and reliable in the Mexican population – for this, two techniques were used: Cronbach's alpha and the 'two halves' technique (Polit and Beck 2004).

To reach a total score, the scores on each of the 12 questions of the final test of the PIH scale were

**Box 2 Partners in Health scale: self-care questions**

**Score the following from 0-8 (0=very little, never, not very well; 8=a lot, always, very well):**

1. Overall, what I know about my health condition(s) is:
2. Overall, what I know about the treatment, including medication, of my health condition(s) is:
3. I take medications or carry out the treatments asked by my doctors or health worker:
4. I share decisions made about my health condition(s) with my doctor or health worker:
5. I am able to deal with health professionals to get the services I need that fit with my culture, values and beliefs:
6. I attend appointments as asked by my doctor or health worker:
7. I keep track of my symptoms and early warning signs (blood sugar levels, peak flow, weight, shortness of breath, pain, sleep problems, mood):
8. I take action when my early warning signs and symptoms get worse:
9. I manage the effect of my health condition(s) on my physical activity (walking, household tasks):
10. I manage the effect of my health condition(s) on how I feel (that is, my emotions and spiritual wellbeing):
11. I manage the effect of my health condition(s) on my social life (how I mix with other people):
12. Overall, I manage to live a healthy life – no smoking, moderate alcohol, healthy food, regular physical activity, manage stress:

added together; the higher the score, the better the self-management. To analyse distribution of the findings, the Kolmogorov-Smirnov test was used, showing that the data were not normally distributed. To analyse differences between groups – for example, diabetes patients, cancer patients and hypertension patients – the Kruskal-Wallis test was used. The Mann-Whitney U test was used to analyse differences in findings between the sexes. The statistical program SPSS version 18 was used.

**Ethical approval** Before starting the study, informed consent was obtained from each participant and the project was reviewed by the research and ethics committee of the university's school of nursing and the ethics commission for the hospital. Written permission to translate and validate the tool was also obtained from the authors of the instrument.

## Results

The sample consisted of 391 (71%) women and 161 (29%) men, with an average age of 57, ranging from 19 to 87 years old. Distribution according to diagnosis found that 150 (27%) had hypertension, 100 (18%) had diabetes and hypertension, 203 (37%) had diabetes, and 99 (18%) had cancer.

**Validation results** To ensure cultural appropriateness, results of the pilot suggested changing some terms so they were easily understood by the study population, without changing the context of the original question in English.

The reliability results for Cronbach's alpha were 0.8 and, according to the different dimensions, 0.7, 0.8 and 0.7 respectively, indicating a good reliability of the instrument (the closer to 1, the higher the reliability). The scale is, therefore, a highly reliable 12-item test (Table 1).

The original instrument considers four dimensions or themes: knowledge (items 1 and 2); dealing with/managing side effects (items 9, 10 and 11); recognising and managing symptoms (items 4, 6, 7, 8 and 12); and treatment adherence (items 3 and 5). The results of the exploratory factor analysis account for three dimensions: knowledge (items 1 and 2); adherence (items 3, 4, 5, 6, 7 and 8); and dealing with or managing side effects (items 9, 10,11 and 12). Items related to adherence and shared decision making with health teams are merged under the adherence theme.

## Self-management behaviour results

The result of the sum of all the questions of the instrument was obtained. The overall average score of the PIH scale was 81, out of a maximum of 100 and a minimum score of 11, where 100 indicates good self-management of chronic conditions. In relation to knowledge of disease and health, an average score of 69 was achieved, with a minimum of 0 and maximum of 100; in relation to adherence, a mean of 83, with a minimum of 0 and maximum of 100, was scored; and management of signs and symptoms scored an average of 82, with a minimum of 13 and maximum of 100. This indicates the dimension of knowledge of disease and health was the most deficient area of self-management.

In relation to the analysis of differences between disease and self-management, the statistical test showed significant differences ($p<0.05$) in the overall index, the theme of adherence and symptom management group. The group diagnosed with cancer presented higher ranges and the diabetes group presented lower ranges compared to the hypertension and diabetes groups and hypertension groups. This indicates that self-management differs by disease group; self-management is better in patients with cancer, while patients with diabetes have poor self-management (Table 2, page 36).

Differences were also found by sex, with the female group presenting higher ranges than the male group (Table 3, page 37), suggesting women have better self-management than men. No differences were found by age.

## Discussion

**Validity of the instrument** This instrument evaluates self-management, taking into consideration patients' knowledge of their condition and adherence to treatment, which involves compliance, negotiating treatment plans with health teams, management of symptoms, and management of the physical, psychological and social implications of chronic disease. The validation results allow us to affirm that this instrument has reliability and validity to be applied in a similar population. Validation of this instrument will hopefully enable us to use a methodological tool to assess the skills

**Table 1** Statistical reliability for each dimension (Cronbach's alpha)

| Dimension | Cronbach alpha | Number of elements |
|---|---|---|
| Knowledge | 0.784 | 2 (items 1 and 2) |
| Adherence | 0.860 | 6 (items 3,4,5,6,7,8) |
| Symptom management | 0.742 | 4 (items 9,10,11,12) |
| Average/total | 0.878 | 12 (see Box 2) |

**Table 2** Differences according to disease self-management (Kruskal-Wallis test)

| | Diagnostic | *N* (total: 552) | Average rank | *P* value |
|---|---|---|---|---|
| General index | ■ Hypertension | 150 | 264.91 | 0.003 |
| | ■ Diabetes and hypertension | 100 | 284.64 | |
| | ■ Diabetes | 203 | 256.68 | |
| | ■ Cancer | 99 | 326.49 | |
| Knowledge | ■ Hypertension | 150 | 276.74 | 0.298 |
| | ■ Diabetes and hypertension | 100 | 301.64 | |
| | ■ Diabetes | 203 | 264.81 | |
| | ■ Cancer | 99 | 274.72 | |
| Adherence | ■ Hypertension | 150 | 257.01 | 0 |
| | ■ Diabetes and hypertension | 100 | 273.87 | |
| | ■ Diabetes | 203 | 241.13 | |
| | ■ Cancer | 99 | 381.21 | |
| Symptom management | ■ Hypertension | 150 | 258.05 | 0.010 |
| | ■ Diabetes and hypertension | 100 | 271.12 | |
| | ■ Diabetes | 203 | 270.03 | |
| | ■ Cancer | 99 | 323.16 | |

and self-management abilities of people with chronic disease and design more effective targeted interventions. We also hope it will contribute to future studies that promote self-management.

We argue that this tool enables initial evaluation of self-management in people with chronic illness and, unlike other instruments, can be used in relation to any chronic disease and applied by healthcare professionals working in primary care settings. It provides a first screening of self-management behaviours in people with chronic illness and enables staff to monitor and evaluate patients, and assess the effectiveness of educational programmes that promote self-management.

**Self-management** In the context of this study, self-management is based on the concept model by Flinders (Lawn *et al* 2009) and refers to patients' ability to understand the nature of their condition and to manage and organise their access to important elements of their care. Patients who self-manage effectively understand their illness, can recognise early warning signs of deterioration and take appropriate action, can manage their lifestyle for optimal health outcomes, and can work effectively with healthcare providers and care-givers.

The results of this first exploration of self-management behaviours have identified barriers, such as patient deficiencies in knowledge of their disease, which may be different depending on the type of disease and gender, as shown by the results in relation to diabetes. The results also suggest that women are better at self-management than men.

There are no other studies with which to compare our findings, except for the group with diabetes, where research has also shown deficiencies in knowledge among patients (Medellín-Vélez 2007, Vargas *et al* 2012) in a similar Mexican population. No studies have been found for patients with cancer and hypertension. The findings of this study suggest that patients in the cancer group have higher levels of knowledge and adherence than other groups, which may be explained by the fact that this group receives treatment at hospitals, unlike diabetes and hypertension patients, who administer treatment themselves.

As this is a first exploration of self-management in these groups, the authors suggest that these findings require more research. Differences identified by sex of the patient, where women seem to be better at self-management than men, suggest that further research from a gender perspective would also be useful.

**Table 3** Differences in self-management by gender (Mann-Whitney U test)

| | Gender | *N* (total: 552) | Average rank | *P* value |
|---|---|---|---|---|
| General index | ■ Female<br>■ Male | 391<br>161 | 288.06<br>248.43 | 0.008 |
| Knowledge | ■ Female<br>■ Male | 391<br>161 | 282.93<br>260.87 | 0.134 |
| Adherence | ■ Female<br>■ Male | 391<br>161 | 289.14<br>245.80 | 0.003 |
| Symptom management | ■ Female<br>■ Male | 391<br>161 | 281.91<br>263.35 | 0.207 |

## Conclusion

The Partners in Health scale can be applied to assess self-management behaviours in populations living with chronic health conditions similar to the participants who took part in this validation, including diabetes, hypertension and cancer. The authors also recommend that the instrument is validated in other Latin American contexts. The results further suggest that there is still much to be done to promote self-management in people with chronic onditions, and further research is needed into self-management from a gender perspective, not only in the Latin-American context.

### Online archive

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**Conflict of interest**
None declared

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