

Providing and receiving self-management support for chronic illness: Patients' and health practitioners' assessments

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ABSTRACT

INTRODUCTION: Providing care for people with chronic illness is a major issue for health practitioners around the world, especially as populations age. Encouraging self-management is beneficial in terms of relieving the burden on the health system and promoting better health and adherence to medication and advice amongst this group.

AIM: To measure the level of self-management support being provided to and received by people living with chronic illness in a District Health Board (DHB) region.

METHODS: Self-report questionnaires (PACIC) were completed by 341 people living with chronic illness to measure the self-management support they receive from general practitioners and nurses. A modified version of the PACIC was used with 12 GPs and 77 primary health nurses in the same region to assess the provision of self-management support.

RESULTS: Patients' assessments suggest that they are receiving intermittent self-management support for their chronic illness. A comparison of ratings of different health practitioners revealed that nurses were reported to be providing support more consistently than GPs. The health practitioners rated themselves as providing self-management support more often than the patients reported receiving it. Many clinicians also suggested that not all forms of support are appropriate for everyone, suggesting the need to tailor support to the individual.

DISCUSSION: Chronic illness support needs to be considered within the context of the individual and to be embedded in an ongoing relationship between the person and the provider. Findings highlight the benefits of a multidisciplinary team approach to self-management support and education in chronic illness care.

KEYWORDS: Chronic disease; self care; primary health care; primary nursing care; physicians, family

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Introduction

Chronic conditions have been identified by the World Health Organization as the twenty-first century health care challenge due to the escalating incidence and the social and economic costs which accompany them. In 2006 the NZ National Health Committee presented a report to the Minister of Health which outlined chronic conditions as a major driver

for inequalities and an area where there were significant opportunities to review and revise the nature of service provision.¹ In line with international literature, a key component of that advice was a move towards increasing the capacity of people with chronic illness to better understand and manage their own conditions. This has become variously known as self-management or self-care support.

Self-management has been defined as:

1) engaging in activities that promote health, build physiologic reserve and prevent adverse sequelae; 2) interacting with health care providers and adhering to recommended treatment protocols; 3) monitoring physical and emotional status and making appropriate management decisions on the basis of the results of self-monitoring; and 4) managing the effects of illness on the patient's ability to function in important roles and on emotions, self-esteem and relationships with others.²

This suggests the need for self-management support from health professionals, defined as 'the systematic provision of education and supportive interventions to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support'.³

The need for self-management is twofold; firstly, engaging patients in the decisions and management of their condition(s) results in better adherence to medication, more positive health behaviours and better outcomes, even when treatment has proved ineffective,⁴ and, secondly, self-management can reduce the strain on the health system of coping with the increasing level of chronic illness in the population. Self-management is a core dimension of the Chronic Care Model⁵ which is widely accepted in the US and around the world. Bodenheimer⁶ suggests that the provision of self-management support requires a team approach to: giving information; teaching disease-specific skills; negotiating health behaviour change; providing training in problem-solving skills; assisting with the emotional impact of having a chronic disease; providing regular and sustained follow-up and encouraging active participation in the management of the disease.

The aim of this study was to measure the level of self-management support being provided for and received by people living with chronic illness in the MidCentral DHB region. Here we report on the completed first phase of a two-phase study. Phase one will be replicated 15 months later to assess naturally occurring developments in recognition that this is an area of ongoing learning and development for primary health care services.

WHAT GAP THIS FILLS

What we already know: Facilitating self-management is an important aspect of chronic illness care, both to decrease demands on the health system and to improve patient outcomes. Previous research has explored the support provided by health practitioners, but little consideration has been given to how the impact of that support might differ when provided by health practitioners from different disciplines.

What this study adds: This study shows that nurses are perceived to provide more self-care support than GPs. A multidisciplinary team approach to the provision of chronic illness care is likely to best meet the needs of individuals living with chronic illness.

Methods

Sample

In this study, two sets of data were collected; one from people living with one or more chronic illness/es, the other from general practitioners (GPs) and primary health nurses providing chronic illness care. The patient sample was recruited by sending letters of invitation; firstly to all who had attended any ambulatory chronic illness clinic during the previous 18 months, secondly via a company managing health services provided through Primary Health Organisations (PHOs) in the community, and thirdly through a Maori health provider. From these invitations we received 400 expressions of interest. Surveys were sent out to this group and 341 usable forms were returned. This reflects a response rate of 85.3% from the expression of interest pool. For the clinician sample, letters of invitation and questionnaires were also sent to GPs and primary health nurses in the DHB and 89 were returned—77 from nurses and the remainder from GPs.

Materials and procedure

The Patient Assessment of Chronic Illness Care (PACIC)⁷ was used to measure self-management support. This 20 item self-report questionnaire was designed to evaluate five types of self-management support representing five of the six aspects of the Chronic Care Model. The items have consequently been developed to provide a total scale and five subscales which, according to the authors, are defined as follows: *Patient activation* involves actions that solicit patient input and

involvement in decision-making; *Delivery system design/Decision support* includes actions that organise care and provide information to patients to enhance their understanding of care; *Goal setting/Tailoring* means acquiring information for and setting of specific collaborative goals; *Problem solving/Contextual* is represented by considering potential barriers and the patient's social and cultural environment in making treatment plans; and *Follow-up/Coordination* involves arranging care that extends and reinforces office-based treatment, and making proactive contact with patients to assess progress and coordinate care.⁷ The PACIC requires respondents to rate the frequency with which certain types of care are provided on a 5-point scale ranging from 'almost always' to 'almost never', numerically scored as 5 to 1 respectively.

Two sample questions are:

During the last 12 months when receiving care for my chronic illness, I was...

...helped to make plans for how to get support from my friends, family or community.

...sure that the health professional thought about my values and my traditions when they recommended treatments to me.

Scores are averaged to provide a total and subscale scores within the range of 1 to 5. With respect to internal consistency of the scales, Cronbach's alphas have been reported to range between 0.77 and 0.90.^{7,8}

In the current study, participants were asked to rate two health professionals; firstly, their GP

or practice nurse (whoever they felt to be most responsible for their day-to-day chronic illness care) and, secondly, another health professional who they felt provided care in relation to their chronic illness/es. The PACIC, plus some health and demographic questions comprised the patient questionnaire which was posted out with a reply-paid envelope to those who had responded to the letter of invitation. A reminder letter was sent to those who had not returned the questionnaire within a month.

The health professional questionnaire primarily consisted of a modified version of the PACIC, hereafter referred to as the MPACIC. The modification changed the question stem to fit the context of care provided rather than received in order to amend the questionnaire for use with health practitioners rather than patients. Questions about cultural sensitivity were also included. Further detail is provided elsewhere.⁹

Results

The patients ranged in age from 23 to 93 with a mean age of 68.2. There were slightly more men (189, 55.4%) than women; 270 (80.4%) were NZ European and 49 (14.6%) identified as Maori. Over half of the respondents (176, 58.8%) indicated they were living on less than \$20,000 per annum. The chronic conditions listed were varied with just over a third of the sample (119, 35.2%) indicating they had only one condition, the other two-thirds living with two (112, 33.1%) to seven (20, 0.6%). The main conditions experienced, and the percentage of the sample affected were: cardiac (212, 62.7%), diabetes (136, 40.2%), respiratory (94, 27.8%) and pain (94, 27.8%). Ratings of the impact of their chronic illness on quality of life ranged from 0 to 10, thus representing the full scale where 0 represented no effect and 10 an extreme effect, with a mean score of 6.4 and a mode of 8.0.

Of the 341 patients, 307 (90%) provided ratings of a GP as health provider and 180 (52.8%) rated a nurse. As a number of participants rated both a nurse and a GP, the ratings could not be considered independent. Therefore no inferential statistics are reported in this paper. The mean total and subscale scores for the patient ratings are

Table 1. Comparison of mean PACIC and MPACIC subscale scores

	PACIC GP	PACIC nurse	MPACIC
Patient activation	2.9	3.5	4.3
Delivery system/practice design	3.1	3.7	3.8
Goal setting/tailoring	2.3	3.2	3.8
Problem solving/contextual	2.8	3.5	4.1
Follow-up/coordination	2.6	2.9	3.8
Total scale	2.7	3.3	4.0

presented in columns two and three of Table 1. The possible range of score was 0 to 5 and it can be seen that the range reported was from 2.3 to 3.7. A comparison reveals that nurses are rated more highly than GPs on all aspects of self-management support. The magnitude of the means shows that, on average, nurses are providing self-management support sometimes to most of the time whereas GPs are generally not or sometimes providing it. The fourth column provides mean scores for the health professionals' ratings of their own provision of self-management support. They ranged from 3.8 to 4.3 (possible range 0 to 5) and are notably higher than the patient ratings of the support they receive. It is also apparent from comparing the rank order of the subscale scores that the aspects of self-management support provided by nurses and GPs are similarly ordered with delivery system design being rated highest for both practitioner groups and patient activation second. The only difference was the reversal of placings for the two lowest rated aspects, goal setting and follow-up. A comparison with the MPACIC scores showed that health professionals considered themselves to be providing the best support in the area of patient activation with problem solving scoring second. The other three aspects were all equally rated.

One hundred and twenty-two participants provided ratings of both a GP and a nurse and, within these pairs of ratings, mean PACIC scores were 2.8 and 3.2 respectively. Although the participants were asked to provide ratings of care received from two health practitioners, not all had two to rate. To see whether those with two were better off than those with one, a comparison was made between the one score of those participants with only one chronic care provider and the best score of those with two. Results showed that the mean score was 0.3 (on a 5-point scale) higher for those with two health practitioners, typically a GP and a nurse.

The health practitioners were invited to add comments to their ratings and many of the comments focussed around the notion that the types of support listed are not all appropriate for every individual, and neither are they all appropriate to provide at every meeting.⁹ For this reason many health professionals were choosing to provide

self-management support sometimes or mostly rather than nearly always. Care Plus was cited as being an ideal way to deliver self-management support.

Discussion

The patient data revealed a variety of reasons why this group required self-management support. Many were living with more than one chronic illness, which was having a pronounced affect on their quality of life, in impoverished circumstances. Pain was identified as being a problem for nearly a third of the participants. We previously found that patients were keen to achieve a sense of ownership of their condition and expressed a desire to understand, plan realistically and anticipate the course of their condition.¹⁰ Much of this was expressed as a need to have their personhood rather than their illness

At the heart of self-management support is the nature and quality of communication in clinical encounters and the best use of team members to provide aspects of care

as the focus of clinical encounters. Literature on self-management identifies the need for relating to individuals in terms of their personal context including the particular capacity of each individual to manage changes and demands in their life.

The scores on the various aspects of self management support, as identified by the subscale groupings, show remarkable consistency across the three sets. It appears that follow-up and goal setting are the areas of self-management support that are most in need of attention within the current system. At the heart of self-management support is the nature and quality of communication in clinical encounters and the best use of team members to provide aspects of care. The apparent difference between how GPs and nurses were rated by chronic illness patients in this study highlights the need for a team approach to providing self-management support. As noted by

Wagner,¹¹ much of what is needed is behavioural counselling, which may be considered outside the job description of most GPs and better suited to the nurse role in chronic care service delivery. Thus, if a proactive team-based approach is utilised, the patient should have access to a comprehensive range of primary health care clinicians who are well placed to complement the care provided by GPs and specialists.

Our results suggested that, on average, patients receiving support from more than one practitioner rated the care they received more positively than those with less support. It may well be that they were being provided with different forms of support from different practitioners, thus benefiting from exposure to a care team.

The reported difference between the levels of self-management support patients indicated they

a similar situation, what the impact may be on a patient's lifestyle, or, based on our knowledge of patients derived from being their family doctor, judging what they may consider appropriate'. This approach also aligns with the notion that self-management support needs to be embedded within an ongoing relationship between patient and health professional; the same approach doesn't suit everybody.¹³ Enabling patients to incorporate self-management into their daily routines requires getting to know them in order to develop self-management plans collaboratively.⁶ Similarly Willis¹² talked about the need for patients to have 'true autonomy' defined as providing information they want or need, but in a form that they can understand, thus becoming partners and enabling them to self-govern. He used a rugby team analogy to highlight the importance of one person's autonomy not being allowed to overcome another's and this could be applied equally well to a chronic care team where the successful approach enables doctors, nurses, other health professionals and patients themselves to exercise their autonomy both individually and as a team to achieve the most positive outcome for the patient.

Care Plus was considered by the health professionals sampled to be a useful vehicle for administering self-management support, primarily due to the time it made available for individual consultations. The programme was introduced for people with chronic conditions in July 2004, with the aims of improving chronic care management, reducing inequalities, improving primary health care teamwork and reducing service costs for high need primary care recipients. While Care Plus was not mentioned by our patient sample—perhaps because they were unaware of their involvement in it—a national review of the Care Plus programme¹⁴ found that patients felt their care to be better structured, appreciated the consultation focus on their chronic illness, had on average accessed four more consultations per annum than previously, and had mostly (80%) received a care plan. The review identified a number of barriers to the implementation of Care Plus; for example remuneration, the need for extra nurses, and the space and time required, but concluded that most individuals (professionals and patients) were generally supportive of the programme. The few comments provided in

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are receiving, and that which health professionals consider themselves to be providing, is interesting. It may reflect an inconsistency between patients' and health practitioners' knowledge and beliefs about what constitutes care, and specifically self-management support. The findings also need to be viewed in light of the question that was being answered. Health practitioners were rating what they generally do in relation to chronic illness care; the patients were rating the self-management support they personally receive.

A number of practitioners commented that some of the listed types of support were inappropriate for a number of clients or stated that they carried them out on occasion but not at every visit. This may be an example of Willis's¹² definition of providing information which, he suggests, should not just be the transmission of facts but encompass 'how other people have responded in

this study concerning Care Plus suggest that it is well regarded by those implementing it, but the extent to which it is deployed in the study region is patchy.

Glasgow et al.⁵ quote the adage ‘what gets measured gets done’ and that was one intention of the current study. It was hoped that the process of responding to questions regarding self-management support would increase awareness of what such support involves and encourage health professionals to reflect on, and perhaps even alter, their behaviour. The planned phase two of the study will provide the opportunity to assess developments.

Limitations

Although there may have been some link between the data sets as some of the patients involved in the study would have been receiving care from some of the health professional participants, patients were not asked to identify who they were rating by name and doctors and nurses were not required to identify themselves. It would be useful in future research to link the sets of ratings in order to identify areas of self-management support where there were apparent disparities between what health professionals consider themselves to be providing and what patients feel they are receiving.

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COMPETING INTERESTS

None declared.