

Long-term conditions care in general practice settings: Patient perspectives

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ABSTRACT

Objective

To explore the experiences of people with long-term illness when accessing general practice services.

Method

In 2006, over half of 147 survey respondents agreed to participate in face-to-face interviews about their long-term illness care. A sub-sample of 32 participants was selected for interview, ensuring equitable representation from cardiac, diabetes and respiratory ambulatory care databases.

Results

Although satisfied with the overall provision of general practice services, interviewees anticipated reactive responses. They described broader needs for education

about their conditions, interpretation of care processes, and ongoing decision support within the context of their everyday lives.

Conclusions

The current general practice model of care struggles to address the broader needs of people with long-term conditions; and practice nurse roles within that model appear to be significantly constrained.

Implications

This evidence suggests that currently general practice nursing roles are not always able to facilitate the desired impetus to support increased self-care support for people with long-term conditions.

(NZFP 2008; 35: 319–323)

Introduction

In 2005 and 2006 a study considered dual nursing and patient perspectives of evolving primary health care nursing for people living with long-term illness, in two specific Primary Health Organisations (PHOs) within a provincial district health board. The study was undertaken at a time when the implementation of the Primary Health Care Strategy¹ and the care and management of people with long-term conditions are of paramount interest in the health sector. The District Health Board (DHB) managers who funded this research and the research team were particularly aware of the imperative to increase the level of self-care support

for people with long-term conditions to improve their quality of life, and coincidentally reduce the pressure on health services.^{2,3}

This article focuses on the findings of semi-structured face-to-face interviews conducted with a sub-sample of 32 research participants, who were selected from a larger cohort of patient survey respondents (N=147), to develop a clearer picture of their experiences accessing health services in general practice settings.

Background

Within New Zealand, long-term conditions currently account for over 70% of all health care spending and approximately 80% of all deaths.³ The

National Health Committee report supports change toward more proactive and coordinated health care that focuses on helping people adapt and cope within the context of their everyday lives, instead of simply focusing on the conditions themselves. Authors such as Bycroft and Tracey⁴ recommend a range of practical self-management interventions identified by researchers to improve long-term care outcomes. Emerging patient-centered interventions are beginning to address the loss of autonomy experienced by people with long-term conditions and their family members, as they navigate their shrinking horizons.^{5–7} However, the contextual realities that currently characterise primary health

service delivery limit the opportunities of all clinicians (medical and nursing) initiating, facilitating and supporting people with long-term conditions to achieve relevant health-related goals, in a timely manner and with appropriate support.⁸⁻¹⁰

Method

Ethical considerations

The Central Ethics Committee provided ethical approval for the study (CEN/05/02/003). Participants were first telephoned to confirm their interest in being interviewed, and to establish a time and venue for their interview. Written consent was obtained from participants prior to the start of their interviews.

Participant recruitment and characteristics

The 32 participants interviewed were selected from a larger patient cohort. That cohort had been chosen using diagnostic criteria and a range of inclusion and exclusion criteria from three sources of ambulatory care databases comprising attendees of cardiac, diabetes and respiratory outpatient clinics between February and July 2005. Fifty-nine per cent (N=147) of attendees invited to participate completed self-report surveys, over half of whom also indicated their willingness to be interviewed. When selecting the interviewees the researchers ensured equal representation across the three database sources. Selection also balanced social demographic characteristics such as sex (15 men and 17 women), and urban/rural residential location (15 urban and 17 rural). Interviewees were 68.6 years on average; New Zealand European (27), Maori (4) and Pacific (1). The sub-sample was purposively selected to ensure greater ethnic diversity than the larger cohort.

Data collection

Four members of the research team interviewed patients in their own homes. The questions that guided the semi-structured interviews initially

focused on the participants' general health and their confidence in self-managing their symptoms, before exploring their experiences of attending the general practice setting and accessing nursing services. The selected participants were mailed a copy of the interview prompts prior to their interviews. Interviews were taped and transcribed and each participant received a hardcopy to check. No participants requested that any of the transcribed content of their interviews be deleted or altered in any way.

Data analysis

Data were analysed by the principal investigator, to understand the experience of people accessing general practice services for ongoing management of their long-term condition. The inductive analytical techniques drew from those recommended by Denzin,¹¹ Boyatzis¹² and Seale.¹³ Repeat reading of transcripts led to manual identification of patterns, repetitions and commonalities within and across the interview data. The data were then aggregated thematically according to these patterns. A final read cross-checked all interviews for the identified themes and highlighted textual samples which best captured those themes.

Results

Three main themes arose from data analysis. These were:

- The patients' desire for personal connection and guidance;
- General practice as an accessible but reactive service; and
- Limited awareness of the nurse's role in general practice settings.

Needing personal connection and guidance

Participants described a desire for connection, co-ordination, information, interpretation of health education, assistance with planning, having realistic expectations and with negotiating life. Participants described the sense that their condition was being treated in isolation from their particular lived circumstances.

We don't understand a lot and sometimes they don't tell you very much at all. When you are getting older, you find that stress is very easy – so it would help if we could have some way of knowing –

I guess if I knew the right questions to ask they would answer them – but I don't know the right questions to ask.

Data revealed people's sense that their care had a somewhat uniform or prescriptive nature, which did not relate to them as a person with a particular context. Participants expressed a need to have someone who could respond to their individual moments of fear, uncertainty and sometimes panic. In this context there were suggestions offered for the creation of a role which could loosely be described as that of care co-ordination, or more directly as that of partner and navigator for people with long-term illness, with the goal of increasing their ability to self-care.

And nobody's picked up the whole package and said – right this is what it is.

A bit like Citizen's Advice Bureau but a health advice bureau and this person wouldn't really specialise in a set area – a general type of nurse who could direct you to the correct people and one that belongs in that community.

Consistently patients described a need for services that could be identified as nursing services, but equally consistently they resisted interview prompts to consider the practice nurse as being available to them for such services. Indeed, even where the potential of nursing was glimpsed, it was still accepted only with additional conditions applied:

Yes I appreciate that the nurse with the right qualifications and right education – she could be very useful.

General practice as a prompt but reactive service

The general practice environment emerges as a prompt, accessible but reactive service. Participants expressed consistent satisfaction with

the availability and timeliness of general practice services and urban dwellers were also content with accessibility. But it is clear that in the efforts to process a large volume of work, participant encounters are often brief and focused on the immediate presenting problem; sometimes to the detriment of a more comprehensive response and to the provision of structured care. Many participants described their sense of feeling rushed in the encounter:

They rip my blood pressure out and check my lungs and then out the door I go, virtually. You almost get to the stage where you feel guilty if you mention something else that might be wrong with you!

Almost all the participants appreciated that a general practitioner (GP) is available to them at short notice, and they see the GP as the first port of call. Participants valued knowing, and being known by a specific GP. Stories became more diverse however, when the discussion turned to what actually occurred in the GP/patient encounter. In these interviews we attempted to tease out exactly who was providing what care in the practice setting. The picture that emerged demonstrates that GPs provide a number of services that are inconsistent with extensive medical training; for example participants noted:

– *he does everything – blood tests, urine tests etc.*

– *the GP still has to see you first. If you have a cut he will look at the cut and then say – you go and see the practice nurse.*

The attention paid by GPs to such a wide range of tasks in the practice setting may directly contribute to the next theme.

Limited awareness of the role of nurses

Participant comments consistently expressed vagueness about what nurses do in the general practice setting. They almost universally described how busy the nurse was, but then had very little idea about what 'being nursed' might entail. Nursing

is apparently invisible as a service; at least to people with long-term care requirements. Participants seemed clear that the nurses are 'flat out', but did not relate that to services available, or able to be provided, to them:

They are rushed off their feet – there's no two ways about it.

I mean she (nurse) is there when you go in – but for her to do procedures, no. I go straight to the doctor.

Participants frequently spoke interchangeably about nurses, technicians and receptionists. While perception may well be different from reality, it is notable that nurses were not always clearly identified as such by some of these participants:

The GP nurse, yes – she does reception work as well

And the receptionist, she's part nurse too, she knows quite a bit about us...

This may be because nurses are being employed in a range of non-clinical roles. Participants also clearly saw nurses as operating under delegated authority from doctors:

I think sometimes she tells you things that she's not supposed to tell you!

It strikes me that the nurse only does what the GP allows; I think she could do quite a lot more.

Data revealed that people are actually unsure what a nurse might do, even if one was available; and yet the participants articulated a set of needs that could be clearly identified as being the domain of nursing in primary health care. Participant accounts demonstrated low expectation of receiving information, being able to share concerns, receiving guidance and support with planning, and there were minimal reports of health education occurring. Even in settings where participants had experienced one-on-one care with a nurse, the encounter did not seem to feature the kind of structured care and care planning known to be congruent with a nursing approach to care.

I haven't had any follow up and no nurses have given me any information at all.

She didn't really offer advice on food or exercise – I still don't know. No advice from the doctor either.

Discussion

These findings are reported at a time when there is significant concern to improve the quality and co-ordination of services for people with long-term conditions, and a desire to increase people's ability to self-manage their care. They reflected the experiences of participants accessing care in general practice settings within two PHOs, and may be incongruent with variations in other settings where nurse services are deployed differently. Moreover, these results should be considered within the context of the larger study, where complementary patient and nursing survey responses revealed:

- (i) patients with high levels of poverty, high symptom levels and diminished quality of life; and
- (ii) low levels of knowledge and confidence about managing cardiac, type II diabetes and respiratory conditions amongst practice nurses.

With the exception of interviewees who were geographically remote, participants almost universally described the ready accessibility and promptness of general practice services. Largely content with the services provided, they described services being there for them whenever they called. Critically, however, participants also outlined a set of needs that could be described as managing life with a long-term illness. These included a desire for education about their conditions; interpretation of care processes; on-going decision support with anticipating and planning for illness-related circumstances; and managing daily life with levels of illness-related disability.

The needs experienced by people diagnosed with long-term conditions, within the context of their families and health care networks, are seldom revealed or validated by batteries of clinical tests derived from a uni-dimensional biomedical perspective.¹⁴

Nursing models of long-term illness care that prioritise listening to people's constructions of their worlds through their health-illness narratives offer insights about the transitions people encounter, as they discover 'new ways of living, doing and being'.¹⁵ Supporting and patiently encouraging those whose lives have been disrupted by long-term illness facilitates their psychosocial adjustment to sustain their quality of life in the face of the associated losses. Such a relationship best underpins moves towards the goal of increased self care support.

Bycroft and Tracey⁴ note, 'whereas the goal of traditional patient education is 'compliance', the goal in self-management education is increased self-efficacy (the confidence to carry out a specific behaviour) and improved health outcomes.' Participants' comments suggest they have little opportunity to increase their self-efficacy through a partnership with a health professional who has time to focus on their individual circumstances. We argue that nurses should have time to do this, as it is exactly the kind of practice for which an education in nursing prepares. But the interface between the patient and the general practice, as borne out by participants' statements in this study, reflected a predominantly patient-doctor interaction. Nurses were on the periphery, in terms of both practice and of the participants' perceptions of their contributions.

Substantial variation now exists in general practice or PHO environments across New Zealand. There is, however, national consistency in the delivery of primary care services via a largely medical model which, as further borne out by this study, is not considered to adequately meet the needs of globally increasing numbers of patients with

long-term conditions and significant co-morbidity.¹⁶ There is also a degree of national consistency in the structural funding and deployment of practice nurses. GPs mostly employ this section of the primary health nursing workforce, and theoretically they have direct access to capitated funding for provision of their services. There is a tendency for the GP employer and small

business owner to determine the nature of the nursing services, rather than there being a clearer focus on aligning those services closely with the unmet needs of patients.

The New Zealand College of Practice Nurses' strategic plan for 2002–2005¹⁷ has two statements specifically relevant to this paper. These are 'to work collaboratively to enhance the performance of the General Practice team' and 'to form partnerships with patients'. This latter statement is most pertinent to the research in that results reveal the limited extent to which nurses were able to manage the delivery of long-term condition care in a

way that enabled the self care support of the individuals concerned.

Clearly there are challenges in the busy general practice environment to free up nurses' time to attend to this critical area of practice. If nurses in this particular study setting were

doing more of the tasks that doctors are reported as doing, patient exposure to nurses would be increased and opportunity to provide support to manage life thus enhanced. In addition, anecdotal and research reports¹⁸ of registered nurses spending signifi-

cant time on clerical and housekeeping tasks suggest there is potential for realignment of nurses' work even within existing clinical demands. But

for nurses to do this effectively, many would need significantly increased levels of empowerment through increased professional development. In a complex manner, practice nurses' limited access to post-graduate education, as demonstrated in

the survey data, may be both cause and consequence of the situation.

The public also needs an altered perception of nurses and nursing beyond that expressed by study participants. Views expressed complied closely with the notion of an assistant acting under delegated authority. While this may be a feature of this generally older cohort of patients, those ideas are perhaps not being sufficiently challenged at the present time in order to allow for the kind of nurse-patient partnership conducive to increasing self care.

Primary health services need to be reoriented so that they promote and support innovative ways of delivering coordinated, multi-disciplinary, patient-centered interventions that acknowledge the suffering of those living in the community with long-term conditions.¹⁹ Long-term condition experience is importantly influenced by social and personal factors²⁰ but people's experience of general practice in this study is more descriptive of a reactive medical model of care that will take time and effort to change. Any solution is contingent on a primary health care system that enables all the actors within community health care settings to use the potential presented within each clinical encounter, and thereby maximize the opportunities to achieve the best possible positive health outcomes that are associated with appropriately supported interventions.

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Individual vs population health

'What is missing from this picture and what the skilled generalist remembers is that (individual) health and health care depend on taking into account the influences of and the context of the community. The concept "ecology of medical care" emphasises the relations between the population and community, on the one hand, and personal health care, on the other. Therefore, understanding the practice population, with its most prevalent health problems and determinants of health has been at the root of the generalist resurgence of the 1970s and 1980s.'

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Primary care or primary health care?

'Although the concepts of "primary care" and "primary health care" are often used as synonyms, they represent different aspects of the development and articulation of first level care. The subject of this book is not the broad societal strategy of primary health care as laid out at Alma Ata, but rather the more limited area of primary care as a subset of functions or services delivered specifically within the context of health care systems ... Primary care consists of the professional response when patients make first contact with the health care system.'

Boerma W, Coordination and integration in European primary care, in Primary Care in the Driver's Seat?: Organizational Reform in European Primary Care, Saltman R, Rico A, Boerma W, Editors. 2006, Open University Press: Maidenhead. p. 3-21.

GPs and research

'Dismay is expressed at the fact that GPs are generally not involved in higher level research, primarily randomised controlled trials. But GPs are more appropriately involved in what we may think of as basic research. Being the first point of contact with the healthcare system, including healthcare research, such doctors are best positioned to make the observations, formalised as case series or observational descriptive study types, on which hypothesis formation can then be based and tested.'

Birden H. The researcher development program: how to extend the involvement of Australian general practitioners in research? Rur Remote Health 2007; 7(776): 8.