



Patients' views on chronic illness and its care in general practice



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BACKGROUND

General practitioners have described barriers to the uptake of incentives such as the Enhanced Primary Care items introduced to support care of chronic illness. However patients' attitudes toward chronic illness and planned care are not known.

METHODS

A qualitative study of adult patients with chronic illnesses using semi-structured interviews and a focus group, examining their experience of chronic illness and their attitudes toward health care.

RESULTS

Sixteen patients were interviewed; five participated in the focus group. Patients believed that their illnesses were permanent and progressive, and that GPs had little influence over their prognosis. They preferred to access GPs for acute problems rather than anticipatory care, and most could not see a need for care planning.

DISCUSSION

Patient preferences for care delivery may be in conflict with the current reform agenda focussing on anticipatory care provision. Efforts to reform chronic illness care may falter unless this is addressed.

The increasing burden of chronic illness has prompted a major reform to primary health care in Australia.¹ Until now, reimbursements through the Medicare Benefits Schedule (MBS) items have mainly funded episodic care. With the aging of the Australian population and the increasing prevalence of chronic disease, it is becoming clear that planned multidisciplinary care is required to improve management outcomes in chronic illnesses such as diabetes.^{2,3}

The Enhanced Primary Care (EPC) MBS items were introduced in an attempt to encourage multidisciplinary care by providing incentives for general practitioners to work with other health professionals and engage in care planning and case conferencing for complex patients.⁴

In order for EPC items to make a major contribution to the improvement of chronic illness care they must be acceptable to GPs. However, GPs have had problems embracing the items, describing both practical difficulties in their implementation and increased bureaucratic burden as major barriers to their use.⁵⁻⁷

It is equally important that EPC items also engage patients, and yet it has been found that many patients remain unaware of the items.⁸ Moreover, we do not know what

patients with chronic illness think about the delivery of health care.

Methods

Four GPs working in southwest Sydney (New South Wales) recruited a consecutive sample of 16 adult patients (3-5 per GP) who held health care cards and had a chronic or complex illness that the GP believed would benefit from multidisciplinary care. We recruited a sample of patients that reflected a typical general practice rather than those using consumer groups.

We undertook semi-structured interviews in the patients' homes. Topics covered included patients' experiences of living with a chronic illness, health care usage, and difficulties with health care. Each patient was given a detailed personalised description of the EPC care planning process and asked for comments. Interviews were tape recorded, fully transcribed, and thematically analysed with a grounded theory approach using NVivo software.⁹ All patients were then invited to participate in a focus group to discuss the results and provide greater depth and validity to the analysis. Five patients attended.

The study was approved by the South Western Sydney Area Human Service Research Ethics Committee.

Results

Patients varied in age, chronic illness and background (*Table 1*). They had different illness experiences and degrees of health service interaction. They all received disability pensions, and although they had suffered financially as a result of illness, financial difficulties were less prominent than expected. Three broad themes emerged to explain patients' attitudes toward their health care.

Patients' fatalism about their illnesses affected their use of services

'There's no good in me going up there all the time saying I can't breathe too much today. There's nothing she can do about it. You've just got to learn to live with it'.

Most patients believed their illnesses were both permanent and progressive, and that neither they nor their doctors could

significantly influence their future prognosis. Thus, they could not comprehend how principles of preventive care might apply to them. This had important implications for how and when they accessed health care. General practitioner visits tended to be reserved for the treatment of acute problems, or when needing prescriptions or referrals, and 'routine' GP visits were considered to be an inappropriate use of resources. In contrast, patients were generally happy to see specialists for 'routine' follow up. This was at times related to optimism about potential treatments, but remained the case even when accompanied by low expectations about prognosis.

Patients practised 'strategic noncompliance'

'I don't like wasting time with things. If they suggest anything like physiotherapy, if I don't think it will work then I won't go and try it.

Just wasting resources, time and money'.

Patients followed advice that they believed to be useful and achievable. For example, medications were taken as prescribed if they provided symptomatic relief, or if the patient had a clear understanding of their role. Those who did not take medications as prescribed usually did so because they did not perceive any benefits. Similarly, some patients did not follow lifestyle advice such as diet modification and increasing physical activity because they believed such advice to be inappropriate or impractical.

Several patients commented that at the time of diagnosis they were more likely to comply with any advice their doctors gave. However, with increasing experience and knowledge they became more explicit about what they would and would not comply with, becoming more likely to listen to the doctor's advice and adapt it to suit their circumstances.

Table 1. Patient characteristics

Age in years	Sex	Country of birth	Living status	Marital status	Carer status	Main illnesses
52	F	Australia	Alone	Divorced	Carer	Systemic lupus erythematosus, ischaemic heart disease (IHD)
48	F	Australia	Family	Single	Carer	Chronic obstructive pulmonary disease (COPD), breast cancer
57	M	Australia	Family	Single	No carer	Spondyloarthropathy
59	M	Australia	Family	Widowed	Carer	Squamous cell carcinoma larynx, cirrhosis
27	M	Australia	Family	Single	Carer	Multiple sclerosis
59	F	Sweden	Alone	Single	No carer	Morbid obesity, diabetes, hypertension (HT)
62	M	Fiji	Family	Married	Carer	Cerebrovascular disease (CVD), diabetes, HT
60	F	Australia	Family	Married	No carer	COPD, osteoarthritis (OA)
54	M	Australia	Family	Married	No carer	IHD, obstructive sleep apnoea, CVD
51	F	Fiji	Family	Widowed	No carer	Asthma, depression, chronic pain
31	M	Australia	Family	Single	Carer	Developmental delay, visual impairment
32	M	Australia	Friends	Single	No carer	Chronic myeloid leukaemia, schizophrenia
41	F	Australia	Family	Divorced	Carer	Rheumatoid arthritis
60	M	Iraq	Family	Married	Carer	IHD, diabetes
74	M	United Kingdom	Family	Widowed	Carer	IHD, diabetes
65	M	Algeria	Alone	Separated	No carer	Depression, HT, OA

Patients did not see a need for planned care

'Can't really see that having a care plan there'd be a great lot of difference to how I do it now... if there was something on it and I was supposed to do it and I didn't think there was any need, I'd cancel it'.

Most patients did not understand the idea of EPC care planning. Some interpreted care plans to be a health record, some an action plan, and others a record of doctors' appointments. The majority of those who did grasp the concept did not believe they would personally benefit from planned care; consistent with the fatalism described above. Furthermore, all but one of the patients receiving multidisciplinary care believed it was coordinated satisfactorily. However, care coordination was rarely interpreted as the sharing of objectives by their various health care providers. Rather, patients saw their providers as having specific discrete roles, and did not expect them to take a 'holistic' approach.

Discussion

This was a qualitative study involving a small number of patients whose views may not represent those of others with chronic and complex illness. Nevertheless, the extent to which their expectations of general practice differ from the objectives of the current reform agenda cannot be overlooked.

We found patients were reluctant to visit their GPs unless they had an acute problem, and they were unable to see any benefit in planning their care. Patients need to be specifically educated about these benefits, perhaps through consumer groups such as Diabetes Australia or chronic disease self management programs. Patients were noncompliant with care recommendations that they perceived held little benefit. As such, care planning for this group may best progress through a collaborative goal setting model in which health professionals are experts about disease, and patients are experts about their own lives.¹⁰ It is unlikely that a better understanding of coordinated care planning alone would encourage the

patients in this study to attend their GPs in a structured fashion.

Changes to the finer details of the EPC items may provide clarity and decrease the bureaucratic burden for GPs, but will have little impact on the way patients continue to engage with primary care. Instead there must be a commitment to involve patients fully in the process of reform and planned care to ensure that both their needs and preferences are met.

Implications of this study for general practice

What we already knew

- Recent general practice reform is aimed at supporting coordinated care planning for patients with complex chronic illnesses
- GPs face many practical difficulties in implementing the EPC items
- A major barrier is that patients continue to access GPs only for acute episodic care.

What this study adds

- Many patients with chronic illness believe their illnesses are permanent and progressive, and cannot see a role for planned care
- Patients need to be educated specifically about the potential benefits of planned care, and must be included in the development of future reforms.

Conflict of interest: none declared.

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