

Achieving a balanced life in the face of chronic illness

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Abstract. The increasing prevalence of chronic disease is a driver of health system reform in most economically advanced nations. A consistent theme within these reforms is building greater patient-centredness into the health care delivery. This study aims to develop an in-depth understanding of the experience of patients and family carers affected by chronic illness that will be the basis on which to propose policy and health system interventions that are patient-centred. Participants struggled with the ongoing tasks of balancing their lives with the increasing demands and intrusion of chronic illness. Their attempts to achieve a balance were seriously hampered by fragmented services, complexity in navigating health services, relationships with health professionals and others, and co-morbidity. Future policy directions include designing models of care and infrastructure that enable patients and their family carers to balance life and illness, and aligning patient-centred care not only within health services but also with community and social support services.

Additional keywords: chronic heart failure, chronic obstructive pulmonary disease, diabetes, qualitative methods.

Introduction

Prevention, management and treatment of chronic non-communicable illness are major issues facing governments in the 21st century. Most formal health care has previously been oriented towards the delivery of acute and episodic care rather than the complex, long-term care, people with chronic diseases require (World Health Organization 2002; Nolte and McKee 2008). Within health systems, patients have been relatively passive recipients rather than actively engaged in their own care (Nolte and McKee 2008).

The impact of increasing levels of chronic disease is a significant driver of health system reform in most economically advanced nations (Productivity Commission 2005; Nolte and McKee 2008). Health care policy debates have steadily shifted towards preventive care, with a growing emphasis on service integration, coordination, flexibility and

continuity, along with policy and system-wide changes to address the management of chronic disease (Zwar *et al.* 2006; Nolte and McKee 2008). An emerging theme in health policy is building greater patient-centredness into the delivery of health care, particularly in chronic disease management (Coulter *et al.* 2008; Nolte and McKee 2008).

Disease specific and population level health policies for chronic illness emerged in Australia in the 1980s and the 1990s at Commonwealth Government level and more recently, at State and Territory levels. Examples include the 2005 National Chronic Disease Strategy, the New South Wales Health Chronic Disease Program and the Primary Care Partnerships Strategy in Victoria (Glasgow *et al.* 2008). These policies identified health issues and priorities, set frameworks for practice and provided incentives to increase desired activities.

Policy at each level of government acknowledges the need for care to be patient-centred and for services to be integrated, providing continuity of care. Patient-centred care proposes the patient and the family (carer) as the focus of care, health planning and delivery, where their uniqueness – based on disease severity, culture, language, preferences, mores, values and attitudes – is considered and acknowledged when making clinical and care decisions. This requires recognition of the patient/carer's capacity and limitations to be involved as an active member in the design of their care. It also means health services and care providers work in collaboration with the patient and their family, assisting them to make informed decisions and sharing therapeutic and personal medical information with them (Mead and Bower 2000; Stewart 2001; Coulter *et al.* 2008).

However, current literature in the field suggests services providing care for people with chronic illness fall short of the policy goals, and dissonance between policy, evidence and practice continues in the Australian health care system (Armstrong *et al.* 2007; Harris and Zwar 2007). In Australia this has been attributed to our complex health system characterised by: divided responsibility for the health system among different levels of government and the public and private sectors; little information and decision support and other infrastructural assistance for those who deliver and receive care; workforce shortages; strong traditions of professional independence; and a focus on acute and episodic care through fee-for-service payments, with growing out-of-pocket costs for patients (Armstrong *et al.* 2007; Harris and Zwar 2007; Glasgow *et al.* 2008).

The Serious and Continuing Illness Policy and Practice Study (SCIPPS) aims to develop policy and health system interventions that are patient-centred and support the provision of optimal care for patients with chronic illness and their carers. SCIPPS focuses on three serious and long-term diseases – complicated type 2 diabetes ('diabetes' hereafter), chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD) – which are known to be common, costly and require ongoing care from multiple providers and services.

To develop policy propositions that are patient-centred, we began our enquiry with patient interviews to give explicit priority to their voice. The inquiry aimed to develop an in-depth understanding of the experience of patients with chronic illness and their carers; including their interaction with the health and social support networks, their experiences in managing treatment including medication, daily living and their personal support.

Methods

The study took place in the Australian Capital Territory and Western Sydney, Australia and was approved by relevant university and health service human research ethics committees. All individuals gave informed consent before participating. We conducted face-to-face, semi-structured, in-depth interviews, each between 45 and 90 min duration. The interview questions were initially developed from the Explanatory Model of Illness (Kleinman *et al.* 1978) and designed to assist understanding the experience of chronic illness from an individual's point of view. The interview questions were piloted with 10 participants then modified to improve clarity of the questions. The pilot data were reviewed and considered adequate for inclusion in the main dataset (refer to Table 1 for the interview guide).

Purposive sampling was used to achieve variation in patient characteristics including age, geographical location, indigenous status and cultural and linguistic background. Participants were patients aged between 45 and 85 years with one or more of the three conditions deemed to be moderate to seriously ill according to their clinician. Eligible patients and carers were recruited via general practitioners, local hospitals, community health services, specialist clinics, consumer organisations, and medical services for Indigenous Australians. Interviews continued until saturation of themes occurred, at which point the dataset was closed (Morse 1995) and completed with 52 patients and 14 carers.

All interviews were electronically recorded and transcribed verbatim, then entered into a computerised qualitative data analysis program, QSR NVivo version 7 (QSR International, Doncaster, Vic., Australia). Qualitative content analysis was

Table 1. Interview guide
CHF, chronic heart failure; COPD, chronic obstructive pulmonary disease

Key questions	Critical incident/prompting questions
Tell me about your experience in living with diabetes/COPD/CHF or as a carer	Can you tell me exactly what happened or can you walk me through the incident?
What concerns you most about your diabetes/COPD/CHF or as a carer?	Why do you think that happened?
What is your understanding of diabetes/COPD/CHF?	How did that affect you/others?
What have been the greatest challenges that you have faced as a patient or as a carer?	How did you cope?
Tell me about your experience with health professionals in terms of managing your diabetes/COPD/CHF or as a carer	What do you think would prevent a similar thing happening again?
Tell me about your experience with health services in terms of managing your diabetes/COPD/CHF or as a carer	–
Tell me about informal support or help other than health care services you are getting as a patient or as a carer	–

performed (Morse and Field 1995) beginning with the 10 pilot interviews. The lead author looked for recurrent words, phrases, or themes – which we termed ‘concepts’ – within the data. An initial coding scheme was developed containing concepts, subsidiary concepts, and their definitions. As the analysis progressed, some of the concepts and subconcepts and their definitions were modified to ensure they conveyed the meaning participants had expressed in the interviews. Fifteen concepts and 170 subconcepts were developed. Assumptions about the relationships within and between concepts were proposed and explored, as were relationships between concepts, demographic and self-reported clinical information. Negative cases, in which a particular concept was not present, were identified and examined. The data collection and analysis was guided by Lincoln and Guba (1985) in terms of credibility, transferability, dependability, and confirmability, to maximise the rigour of the study. The steps are summarised in Table 2.

Additional demographic and self-reported clinical information (i.e. diagnoses, co-morbidity, hospitalisation, medication, length and duration of the index condition, and visits to general practitioners) was collected using a questionnaire administered after each interview. Descriptive analysis of the questionnaire data was undertaken using SPSS version 15 (SPSS 2006). The characteristics of the study participants are summarised in Table 3.

Results

The key concept: balancing life and illness

Key issues emerging from the experience of people affected by chronic illness centre on the struggle to balance their life, including their philosophies and sense of what constitutes a normal life alongside their illness management. The notion of balancing life and illness (BLI) became evident very early in the analysis and was strongly reinforced as the analysis continued. The BLI concept had solid connections to other key issues and was critical in understanding an individual’s response to the management of chronic illness. Through the exploration of the data guided by the following questions, we were able to capture various aspects of individuals’ experiences, which provided a greater understanding of patients’ varying abilities and limitations to strike a balance between life and illness, and the juggling involved in determining the attention and effort they would give to their disease management. The guiding questions are:

- (1) What aspects of their lives did people value?
- (2) What aspects of their illness did people need to balance with their lives?
- (3) What factors influenced the process of BLI?

In the following section we use these questions to structure our discussion and to understand the issues that influence the key concept of BLI.

Table 2. Strategies adopted to ensure rigour of the study

Domains	Strategies developed and implemented
Researcher and process preparation	The research workers participated in extensive trainings and practice to improve interview skills, data management using NVivo7 and data analysis, to ensure optimal quality and consistency of the process. The lead author oversaw the conduct of the process across the two sites. The data collection protocol was developed and implemented.
Pilot	Inclusion of the pilot process assisted with testing out the interview questions and the recruitment process.
Data quality check	Each interview transcript was checked by its interviewer, which improved the accuracy of the transcript and allowed time to reflect on each person’s story in its entirety to assist with identification of key themes. Attempts were also made to identify if inconsistency of the data between the interviews and the questionnaires existed. Interpretation of the data, including the notion of balancing life and illness was confirmed by some members of the local health care consumer organisation.
Reflexivity	The research workers wrote notes soon after each interview, describing their reflections and the principal matters discussed, and wrote memos during the coding process of their feelings emotions, assumptions/biases, thoughts, hypotheses, and theories of their own regarding particular concepts or themes, which were discussed at a team level.
Systematic data management	Management of data using NVivo7 and frequent and regular dialogues through team and individual meetings facilitated the process. Audit trails were possible.
Consistency of data analysis	Development of detailed data analysis protocols and coding schemes, with subsequent revisions, helped the research workers to obtain and analyse the data in a consistent manner and produce audit trails of coding decisions. Assessment of inter-coder agreement using NVivo7 involved segment by segment reviews of the interview texts and the application of subconcepts with segments. All inconsistencies are noted, discussed and resolved (MacQueen <i>et al.</i> 1998). Coding consistency was enhanced by moving from a whole team approach (i.e. all research workers coded the entire coding sets) to a subteam approach (i.e. the team was divided into three coding groups where each group was designated to code a particular set of subconcepts). This strategy resulted in 70–80% of coding consistency between coders. The interpretive analysis of data continued during a writing up process, which was conducted by the research workers in a team environment. The writing and rewriting processes facilitated the research workers to verify and clarify their positions and explanatory statements at a team level.
Richness of data	Purposive sampling and data saturation ensured maximum variability and richness of the data.

Table 3. Characteristics of study participants
NA, not applicable

Category	Category	Patient (n = 52)	Carer (n = 14)
Residence	Australian Capital Territory	26 (50%)	6 (43%)
	Sydney West	26 (50%)	8 (57%)
Sex	Male	28 (54%)	1 (7%)
	Female	24 (46%)	13 (93%)
Age	Up to 64 years	17 (33%)	7 (50%)
	65 years and more	35 (67%)	7 (50%)
Special groups	Culturally and linguistically diverse background ^A	11 (21%)	5 (36%)
	Indigenous Australians	7 (14%)	0
Finance	Experiencing financial difficulties	31 (60%)	11 (79%)
Marital status	Married/de facto/living with a partner	29 (56%)	13 (93%)
Work status	Employed	5 (10%)	2 (14%)
	Not in paid employment	47 (90%)	12 (86%)
Diagnosis ^B	Type 2 diabetes	27 (52%)	7 (50%) ^C
	Chronic heart failure	20 (38%)	4 (29%) ^C
	Chronic obstructive pulmonary disease	17 (33%)	7 (50%) ^C
	More than one index condition	11 (21%)	3 (21%) ^C
	Average length of illness (years)	16.5	21.4 ^C
Visit to GP	Other co-morbid conditions	43 (87%)	11 (86%)
	Fortnightly or more often	12 (23%)	7 (50%) ^C
	Monthly	23 (44%)	5 (36%) ^C
	Bimonthly	3 (6%)	0 ^C
	Quarterly	7 (14%)	1 (7%) ^C
	Half-yearly	2 (3.8%)	0 ^C
Family carer	Only when necessary	5 (9.6%)	1 (7.1%) ^C
	Have a family carer	22 (42%) ^D	NA
	Average length of caring (years)	14.7 ^D	12.5
	Carer's relationship to patient		
	Offspring	6 (27%) ^D	4 (29%)
	Spouse/partner	14 (67%) ^D	10 (71%)
	Other	2 (9%) ^D	0
Carer receives financial assistance	5 (23%) ^D	5 (36%)	
Carer receives informal support	14 (64%) ^D	9 (64%)	

^AIn the 2006 census, more than 21% of Australia's population spoke a language other than English at home (Australian Bureau of Statistics 2007).

^BThe total number combines more than 52 because 10 patients had two of the index conditions and one patient had all three conditions.

^CDenotes the carer's account about the patient's condition and management.

^DDenotes the patient's account about the carer.

What aspects of their lives did people value?

Participants wanted to maximise their quality of life despite the challenge of their illnesses. They said 'by and large I am living a normal life', 'you only live once, life is for living', and 'you get to a point that life's great, enjoy it'. A wife caring for her husband with CHF said:

Life is not dull when you have a chronic disease. We talk about it a lot, about the implications. So I guess what we've tried to do is to maximise the quality of life that he and I have.

Her husband, who experienced angina on a daily basis, said:

Until recently anyhow, it has not sort of made me go, 'Oh my, what a terrible situation!', because I've been enjoying life even with that cloud in the background.

Living a normal life was just as important as managing chronic illness for many. It meant they continued, or wanted to continue, to do things such as eating, socialising, going on holiday, and attending family functions, as they had done previously, despite the limitations imposed by their chronic illness. Participants referred to 'a normal life' in two different ways. The first was to define 'normal' historically, with reference to life before the illness. It was linked to notions of what would be considered normal for well people; 'It just means doing the things that I've done all my life'. Limitations imposed by their illness made their present way of life somewhat below the norm. For these participants, a sense of striving for the 'old' normality was evident. A man in his late seventies with CHF said:

I ignored my heart disease while I was there [on holiday]. I played a lot of golf, I drank a lot of beer, I did

quite a few things that I shouldn't have done, I suppose. So they weren't fruitful in a productive way, but they were fruitful in the fact that we got stuck into life a bit more than we had up until then.

The second way participants spoke of 'normal life' took account of the contemporary reality of the illness. Participants talked about 'normal' in reference to their illness, symptoms and management – what was normal for a person with diabetes, COPD or CHF. These participants were redefining normality for themselves and recalibrating their expectations accordingly. They made changes in lifestyle and were able to lead a normal life in the context of their illness. They accepted and incorporated the limitations caused by the illness and its management. A man with CHF and diabetes contrasted the historic view of his normal diet with the contemporary reality, but concluded his life is fairly normal.

My diet has changed quite drastically. I used to eat anything once upon a time. In fact, I don't think I had any ice cream for about the first 3 years after the heart attack. . . By and large, I live a fairly normal sort of a life. I don't have these things very often.

These two ways of interpreting and embodying what it is to live a normal life were not mutually exclusive. Some participants were striving for the 'old me' in one part of their life while redefining normality in other parts of their life.

Finding the balance

Participants often experienced tension between their desire to lead a normal life and the constraints imposed by their illnesses. BLI involves weighing these competing priorities and deciding on a course of action to achieve a balance. As an 83-year-old woman with CHF said, 'Everything is balanced, got to be balanced. Otherwise the scales will get wobbly'. The scale constantly moves between 'on' and 'off' balance. Over time, most participants developed strategies to achieve balance including cognitive decisions such as accepting the situation and remaining positive; and behavioural changes such as adjusting to lifestyle changes, acting on lifestyle risk factors, learning and planning. For example, a participant might strike a balance between managing blood sugar levels and enjoying dining out where they could be satisfied with their management without forgoing the fun.

What aspects of their illness did people need to balance with their lives?

Chronic illness affected participants in terms of time, activities of daily living, family and interpersonal relationships, social and work activities, and finances, all of which needed to be balanced in their quest for a normal life.

Limitations on time

Participants often spoke about how time had to be purposefully allocated to the logistics of illness management (e.g. visiting health professionals, having tests, taking their daily medications, preparing a special diet) and how time

was lost because of the impact of their illness. Time was considered precious for those with severe illness who felt they had little time left. Participants were frustrated by valuable time being wasted by long waiting times to attend clinics, or multiple appointments with different health professionals on different days. One participant with CHF said:

Getting to an appointment [takes] the whole day. You can appreciate that it's important to me. If I spend half a day somewhere, it's half a day of my life gone and I think 'Well, do I bother?' For what I'm getting out of it, do I need to go? There are other appointments I've got to see but in some of them I wonder if it's worth it.

The demands of their illness reduced the time they had available for 'normal' life. For example, illness characteristics such as shortness of breath, chest pain and fatigue resulted in activities taking longer to complete and when these activities were seen as priorities, less time was available for social or personal activities. A woman in her fifties with CHF stated, 'I find what I could do in an hour now takes me a day'. A man in his sixties with diabetes said, 'What I used to do in a day now takes me all week'.

Carers' time was also affected because their lives often revolved around their care-recipient, especially when that person was highly dependent. Carers felt ambivalent or dissatisfied with their ability to care. They felt guilt and frustration, resenting the impost time devoted to care placed on their own time. The wife of a man with diabetes, whose English was limited, showed her frustration in the following excerpt:

I'm always with him [husband]. He doesn't go [to see doctors] alone by himself. And now I start to say to him, 'Look, I know I must go with you but every time I go with you, it's half a day, sometime all day lost'.

Restricted work and social capacity

Participants frequently noted the limitations their decreased mobility and disease-related symptoms imposed on their work and/or social capacity. Several participants recounted difficulty maintaining their work responsibilities when they had to take time off work to attend appointments with health professionals or fulfil a carer role. They were restricted in their social activities, hobbies or other activities. Their illnesses affected relationships with partners, family members, friends and colleagues. Examples cited included limited options for dining out, restricted opportunities to meet with friends/family, diminished ease of travelling, and the need to be aware of and plan for exacerbations and/or medical emergencies.

Financial limitations

Financial hardship was raised as a key limitation by many of the participants – more extensively expressed by those who were not eligible for pension or government subsidies, were not in any paid employment, were on medication, had comorbid conditions, and/or had culturally and linguistically

diverse (CALD) or Indigenous backgrounds. Financial pressures arose from out-of-pocket costs for medications, supplementary oxygen, specialist and other medical care together with transport costs, the need to make home modifications or purchase assistive equipment. Participants did prioritise expenditure on essential treatment, often compromising in other areas of their lives. Financially vulnerable participants found additional costs problematic and choices often had to be made between expenditure for healthcare and everyday expenses.

What factors influenced the process of BLI?

Factors that influenced the extent to which participants succeeded in BLI, include both those that were amenable to change through changing the type or level of a health linked activity such as health care encounters, knowledge and understanding and practical and psychological supports and those that were difficult to change or could not be changed such as co-morbid conditions and contextual factors.

Health care encounters

Most participants reported difficulties and frustrations in accessing health care services and how professionals provided care. Participants identified negative encounters when health professionals appeared rushed or showed little consideration for their unique needs. Participants said such encounters failed to result in realistic self-management plans. Participants wanted health professionals to demonstrate deep insight into the complex, often multiple, health conditions they had to contend with and the impact of these on their lives. A daughter carer of a mother with diabetes expressed her frustration, saying:

You've got so many different sicknesses and everybody's just concentrating on the one thing and they're not listening to...that she's got other things. I know sometimes it's hard because you've got 10 minutes or whatever you've got with the doctor, starting at 10 minutes and that's the only thing: they always seem to be in such a hurry.

Participants wanted health professionals who were not only knowledgeable, but skilled communicators, manifesting compassion and respect and demonstrating engagement with the particular needs of the individual. Participants believed this empathetic and holistic approach to care would better enable them to self manage. A health professional's flexible approach to patients and carers was valued highly, as this was seen as an indication that their unique needs and situation were understood.

Continuity of care, both continuity of health professional and continuity of information between different services within the health system, was valued by participants. For example, without appropriate discharge planning in place, patients and carers often felt they were ill-equipped to be sent home to manage by themselves after a hospitalisation.

There's a huge gap between being in hospital and being at home, in the sense that – well, there's obviously a lot more people to do things in hospital and they have the medical knowledge, but it's almost as if you're on a different planet, you get one set of things happening in hospital and then you're discharged and it's as if you've been set adrift in a boat without oars and an anchor. . . (wife carer of a man with COPD)

Long waiting times for some health services and difficulties in changing appointment times were major sources of distress for participants. Problems with getting transport to health services, either because of the cost or time involved, amplified their distress.

Knowledge and understanding of the condition, as well as of available health and social services, facilitated BLI by enabling participants to make sound self-management decisions. Patients and their carers often obtained information through education programs and resources and encounters with health professionals. Importantly, experience provided sources of learning; participants learned through their own trial and error processes in living with their illnesses. There was a strong sense of participants wanting easy and ongoing access to information and education.

Practical and psychological support

Having access to formal and informal support (e.g. home help for cooking, cleaning, gardening and grocery shopping; assistance with transport and medication management) to manage the illness enabled participants to better balance their life and illness. They used formal channels such as home care services and respite care as well as informal channels including family and friends. Families were also a source of financial support. Participants emphasised the importance of psychological and emotional support through which they felt reassured, comforted by having someone to talk to, and empowered to maintain social activities and act on lifestyle risk factors. Practical and psychological support often went hand-in-hand, especially in acting on lifestyle risk factors.

Co-morbid conditions

Most participants in the study had more than one condition. Having co-morbid conditions normally required taking multiple medications, which caused varying degrees of confusion among the participants and resulting in undesired pharmacological interactions or adverse effects. Co-morbid conditions had a negative impact on BLI because they amplified illness limitations and interfered with attempts to self-manage by diminishing participants' abilities to act on lifestyle risk factors. For example, a participant with CHF and another with diabetes (both with other co-morbid conditions) said that 'Until last week, I hadn't been to the gym for 5 months [because of a series of falls] I can only walk a short distance, because my knees are bad with arthritis'.

Contextual factors

Contextual factors, such as cultural background, family environment, language, occupation, financial capacity and income status, are less amenable to change and could act as either barriers or facilitators in achieving balance. For example, limited English language proficiency for CALD participants constrained their ability to communicate with health professionals and get support and help from the health system. In cases when interpreting services were provided some participants experienced discomfort with them as they felt their privacy was undermined. Indigenous participants stressed the importance of family and elders in managing their chronic illnesses as providers of information along with Indigenous medical services. They often put the needs of their family over their own needs in terms of work, health and the management of chronic conditions.

Discussion of results and policy implications

Achieving a patient-centred orientation within the health system is growing in emphasis in policy writing in Australia (e.g. Barton *et al.* 2005; National Asthma Council Australia 2007; NSW Health 2008). There is evidence that patient-centred interventions such as shared decision making and individual patients' active engagement in care are linked to improved health literacy, more positive encounters with health care services and better experiences in managing health conditions (Coulter and Ellins 2006, 2007; Coulter *et al.* 2008). A person's total experience is fundamental to a patient-centred approach to health (Lewin *et al.* 2002). Similarly, our findings indicate that the life of a person with chronic illness is not just about being a 'good patient' but about being a 'whole person', and the person is constantly negotiating how multiple aspects of his/her life fit together. To develop patient-centred care, all the aspects of the participant's experience need to be accounted for.

Our study has identified the processes of BLI as a key aspect of the experience of people with chronic illness. The process of BLI highlights the importance of recognising the generally held view that people with chronic illness have to make constant adjustments to their lives, juggling competing priorities in the management of their chronic condition with those that are important to them in getting on with their lives (Thorne and Paterson 1998; Paterson *et al.* 2001; de Ridder *et al.* 2008). Furthermore, the findings draw attention to the importance of embedding the notion of the balancing act in policies and strategies that aim to promote patient-centredness. A central thesis of the process of BLI suggests that to be truly patient-centred there needs to be recognition that the individual's desire to lead what they would regard as a normal life is often the basis on which he or she makes decisions about his or her illness management and these decisions might not always lead to optimal health outcomes.

Because of the complex and long-term nature of what it means to live with chronic illness, or care for someone with the illness, challenges cannot be resolved solely within the health system domain. Our study demonstrates that factors which

impact on patients and carers (e.g. limitations on time, restricted work and social capacity, and economic hardship) arise not only from biomedical factors in individual patients, but also from system-level properties. There is a complex interplay between policies enacted within health and policies enacted within other arms of government. For example, the time management issue, described by participants as their precious lives being wasted while trying to negotiate and respond to the demands of the health system, points to the need to develop and implement connected policies related to social infrastructure as well as new health policy. Our participants pointed to public transport services, health service building environments and parking facilities, access to appropriate housing or housing modification services, the proximity of services to home and the number and type of health services available as important factors to the balance of life and illness. Financial and welfare considerations provide an additional illustration. Participants often identified limited financial resources and insufficient social welfare support (e.g. home care support, transport, and subsidies) as factors affecting the management of their chronic illness. Those factors and the system level properties, combined with the ongoing demands of having to manage their illness, often clash with people's desire to lead a normal life and at times hinder their attempts to balance life and illness. It is essential that health services operate in an integrated way across health and social sectors, taking into account that personal and community resources have a dominant influence on health outcomes.

Wagner's Chronic Care Model addresses this cross-sectoral aspect of chronic illness management to some extent by acknowledging that the social determinants of health, community participation and associated resources and policies in the community influence both the way health care is delivered and its outcomes (Wagner *et al.* 2005; Singh and Ham 2006). Components of the health system such as self-management support, delivery system design, decision support, and clinical information systems must be well supported and resourced because these are critical in bringing about desired health outcomes (Wagner *et al.* 2005). The Coordinated Care Trials in Australia provide other examples of models designed to assist individuals to navigate through the system, make appropriate decisions for their health care through enhanced health literacy, and better utilise primary care services and other community resources. The evaluation of this national initiative suggests that collectively these trials led to individuals' improved access to services, sense of security about their health and interventions, and health-related empowerment (Commonwealth of Australia 2007). However, currently there is no national approach supported by policies in other sectors addressing the wider whole-system issues. A recent initiative in Australia such as the Primary Care Partnerships in Victoria (Victorian State Government 2009) is a good example, at a local level, that brings together people from all service sectors to plan for their local communities, in an attempt to provide integrated and patient-centred care.

The Rudd Government promises to reform the Australian health care system and has launched several policy documents to drive this. These include the National Primary Health Care Strategy and the report of the National Health and Hospitals Reform Commission. Both emphasise the important role that general practitioners, nurses and other health professionals working within the primary and community care sector play in providing integrated, comprehensive primary health care and thus a firm foundation for Australia's healthcare system. Both further emphasise the importance of this sector in the delivery of patient centred care to those with chronic and complex care needs. For example, the recommendations in the final report of the National Health and Hospitals Reform Commission, *A healthier future for all Australians*, emphasise redesigning health care services through such things as the introduction of Comprehensive Primary Health Care Centres and Services, voluntary client enrolment with a 'health care home' and Regional Primary Health Care Organisations (NHHRC 2009). These recommendations are designed to address perennial problems in the Australian health care system, which have surfaced again in our study and include lack of timely access to appropriate services, deficiencies in coordination and continuity of care and lack of service integration particularly for people with chronic and complex care needs. Addressing these issues is long overdue from the patients and carers we interviewed, and requires coherent policy and system support to ensure necessary infrastructures, funding and governance are in place. Attempts to provide integrated primary health care have already been made through initiatives such as HealthOne NSW (<http://www.health.nsw.gov.au/initiatives/healthonensw/index.asp>, accessed 17 September 2009), GP Plus (<http://www.health.sa.gov.au/Default.aspx?tabid=265>, accessed 17 September 2009) in South Australia, and the GP Super Clinic (<http://www.health.gov.au/internet/main/publishing.nsf/Content/pacd-gpsuperclinics>, accessed 17 September 2009) program at a national level. There are also a variety of integrated primary health care approaches worldwide from which lessons can be learned given appropriately rigorous evaluation. Evaluating the experiences of patients and carers, as in our study, provides invaluable perspectives as to how best to implement approaches in the chronic care context and achieve greater patient-centredness.

Applicability of our findings in a larger context may be limited given that data were obtained from two urban regions of Australia; and participants were mainly older people with moderate to severe chronic disease. However, the aim of the study was to inform the development of policy interventions that are sensitive to the local context and time. Our qualitative method used data saturation and negative case analysis to facilitate a comprehensive exploration of the key elements of BLI across individuals' variables. As well, our results triangulate with the findings of other research into the experience of chronic illness (e.g. Hörnsten *et al.* 2004; Barnett 2005; Thorne 2006; Yu *et al.* 2008). Further research is necessary to test applicability and relevance of the process of BLI in other contexts.

Conclusion

The western world is facing major challenges associated with increased levels of chronic disease that demand high levels of care and reveal workforce shortages and competition for health resources. Health systems are looking to reform their care, from one that is principally acute episodic to one that provides good longitudinal care; from a culture of dependence on professionals to one of increasing personal responsibility and self management; and from one that is system or institution focussed to one that is patient focussed. Since the release of the National Chronic Disease Strategy in 2005 there have been various efforts at all levels of Australian government to address the issues of care coordination, continuity, flexibility and service integration. Our study suggests these endeavours have yet to be proven sufficient to the challenge.

Patient-centred care requires incorporation of all complex interactions and contributions within the individual person's context. Future policy direction based on our findings is twofold: the need to design models of care and infrastructure that enable patients and carers to balance their life and illness; and aligning patient centred care not only within health services, but also with community and social support services.

Conflicts of interest

The funding organisation (NHMRC) had no role in the study design, data collection, analysis and interpretation, or the writing and publication of this article. The authors declare that they have no competing interests.

Acknowledgements

The Serious and Continuing Illnesses Policy and Practice Study (SCIPPS) is an NHMRC-funded program conducted at The Australian National University and The University of Sydney and administered by The Menzies Centre for Health Policy. We would like to express our sincere gratitude to all of the patients and the carers who participated in this study. Special thanks are also due to the SCIPPS team members for their support.

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