

Multidisciplinary care: experience of patients with complex needs

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Abstract. The rapidly increasing prevalence of diabetes with its high morbidity and mortality raises the need for an integrated multidisciplinary service from health care providers across health sectors. The aim of this study was to explore the diabetic patients' experience of multidisciplinary care, in particular their perceptions, perceived barriers and facilitators. Thirteen patients with type-2 diabetes admitted to the emergency department of a local hospital in NSW were interviewed and completed a demographic questionnaire. Results showed that patients found it inconvenient to be referred to many health professionals because of multiple physical and psychosocial barriers. Separate sets of instructions from different health professionals were overwhelming, confusing and conflicting. Lack of a dedicated coordinator of care, follow up and support for self-management from health professionals were factors that contributed to patients' challenges in being actively involved in their care. The presence of multiple co-morbidities made it more difficult for patients to juggle priorities and 'commitments' to many health professionals. In addition, complex socioeconomic and cultural issues, such as financial difficulties, lack of transport and language barriers, intensified the challenge for these patients to navigate the health system independently. Few patients felt that having many health professionals involved in their care improved their diabetes control. Communication among the multidisciplinary care team was fragmented and had a negative effect on the coordination of care. The patients' perspective is important to identify the problems they experience and to formulate strategies for improving multidisciplinary care for patients with diabetes.

Additional keywords: diabetes, inter-professional, multidisciplinary care, patient, self-management, socioeconomically disadvantaged.

Received 1 June 2012, accepted 3 September 2012, published online 1 October 2012

Introduction

The Chronic Care Model (CCM) describes six elements that are essential for improving the quality of care for patients with chronic disease (Wagner *et al.* 1996). It aims to create a system that cultivates informed and activated patients with a health care team that is proactive and prepared. A feature of the CCM that has been shown to be effective is delivery system design and the important role of the multi-disciplinary team in planned follow up to support self-management (Dennis *et al.* 2008). The Innovative Care for Chronic Conditions (ICCC) further expanded this to include the patient's support networks, such as their family, with the aim of shifting the patient from being a passive recipient of care to being an active member of the care team (Epping-Jordan *et al.* 2004). The patient/family – health care team dyad central to the CCM model was further extended in the ICCC to include community partners providing an ideal seamless transition between hospital, home and community. This may

involve supporting patients in gaining self-management skills, addressing broad needs affecting care, communicating with health professionals, adhering to follow up and monitoring treatment.

As a result of this shift toward proactive management of chronic diseases across different levels of care, patients are increasingly interacting with several specialist health professionals. While integrated multidisciplinary management can provide optimal care for patients with chronic disease, implementation of this in practice has proven to be challenging (Harris *et al.* 2008). Concerns have been raised about continuity of care and the impact of this on the patients receiving care (Kirby *et al.* 2008). Under the Australian Medicare Team Care Arrangement (TCA) initiative, GPs may refer patients with chronic diseases to at least two allied health professionals for coordinated adjunctive care. TCA collaborations require two-way communication between service providers and regular

reviews. Gaps in service delivery are evident especially when coordination is not facilitated by co-location and good communication; including electronic communication support such as those proposed by Personally Controlled Electronic Health Records (Simons *et al.* 2005; Steinbrook 2008).

Compounding the chronicity and systemic complications of diabetes, patients also have to deal with complex sociocultural and economic issues. Studies have shown that patients from disadvantaged areas are especially vulnerable to poor diabetes outcomes (Schillinger *et al.* 2002) and they are often the people who experience more problems accessing and navigating the system and may result in them using the emergency department (ED) to manage their chronic disease (Kirby *et al.* 2010). This paper aims to describe the views and experiences of patients regarding the multidisciplinary care they received for their diabetes and the facilitators and barriers to taking part in this care.

Methods

The study was set in a local district hospital in metropolitan NSW. The hospital services a socioeconomically disadvantaged population; 49% of people are born overseas and 61% speak a language other than English at home (ABS Census data 2006).

Data from FirstNet, an ED information system, was reviewed to identify patients with a 'principal diagnosis' of diabetes presenting to the ED in 2009. The FirstNet diagnosis was verified by examining the ED discharge summaries or the electronic medical record (Powerchart) for those cases admitted to a ward (Liaw *et al.* 2011). All patients with a verified diagnosis of type 2 diabetes were sent a letter inviting them to take part in a 45-min semi-structured interview with one of the researchers (DM). Patients were interviewed using the guide outlined in Table 1; however, they were invited to expound on their issues of concern.

Patients were asked about what they thought of their diabetes care, the barriers and enhancers and the coordination and communication between the patient and health professionals and among their health care team members. In addition, four carers who were family members of patients were also interviewed because they were present and the patients were not confident in their English language skills. Patients also completed a brief demographic questionnaire assisted by the researcher (DM).

All the patient interviews were completed between February and August 2010. The interviews were audio recorded and transcribed verbatim. Data were analysed thematically using NVivo 8 (QSR International, Sage, LA, USA). Themes were coded by the researcher (DM) and discussed in detail with the research team. This was subsequently analysed in conjunction with data obtained from the questionnaire.

The study was approved by the Sydney South West Area Health Service and University of New South Wales Human Research Ethics Committees.

Results

Examination of the FirstNet data identified 66 patients with diabetes admitted to ED and in the ward in 2009 of which 18 were excluded because they were not contactable, lived outside the area or were too sick to give consent. Letters were sent to the remaining 48 patients and 13 agreed to take part in the study. The reasons given for non-participation included a lack of confidence in their English language ability, were too sick or too busy. Of the 13 patients who participated in the study, eight were admitted to the ward due to diabetes and its complications, while five were admitted for other non-diabetes-related causes. The 13 participants were mostly socioeconomically disadvantaged, on a pension and from a non-English-speaking background (Table 2).

The GP was perceived to be the coordinator of care for 10 of the patients, while two patients claimed to self-coordinate their care. Five patients answered positively when first asked whether they were referred to other health professionals and affirmed that they knew they were being managed by a team. However, as the interview progressed it was made clear that all nine patients had been referred to specialists and health professionals earlier on but four of these patients did not think that their diabetes was being managed by a team as they attended only one appointment or none at all. Patients also included previous experiences in being managed by a team. Four of the patients were not referred as they or their GP felt they did not need the referral.

Views of multidisciplinary team care

When patients were asked about what they thought about having a team of health professionals manage their diabetes, most of them (11/13) said that being referred to different professionals was inconvenient because of the amount of time involved to schedule and attend the appointments with each health professional, lack of transport, travel distance, long waiting times and lack of social support. Having many health professionals also increased the number of medicines they were taking as each was seen to prescribe different sets of medication for different conditions. They also found it inconvenient to have to re-tell their medical histories to each health practitioner they visit. One patient with multiple health professionals takes a list of her medications with her for fear of forgetting the names of the medicines when she visits her many doctors.

I don't like too many people managing my care, my medicine list gets too long, I don't speak English well,

Table 1. Interview guide

Semi-structured interview guide

1. Were you referred to other health professionals by your GP? Who coordinated your care?
2. What did you think of having many health professionals taking care of you?
3. What were the things that concerned you about having many health professionals taking care of your diabetes?
4. Was there a benefit in having many health professionals taking care of your diabetes? Did you have better control of your diabetes when you had many health professionals taking care of you? Why or why not?
5. How do you think your health professionals communicate with you and with each other about your care and referral?

Table 2. Patient demographics

Age range	37–80 years
Gender	8 males, 5 females
Unemployed	7
Non-English speaking background (NESB)	7
Aboriginal	2
Newly diagnosed diabetic	5
Diabetes duration	0–15 years (average, 7.5 years)
Patients with concomitant chronic condition	10
Treatment	Tablets and insulin – 9 patients. No treatment despite high blood glucose levels – 2 patients

I have to make many appointments and sometimes my daughter cannot take me. (female, 67 years)

Only two people thought that being managed by a team would improve their diabetes care. One patient felt that the hospital was better equipped to take care of diabetic patients because the expertise is all in one location.

If there are more experts taking care of my diabetes like it is in the hospital and they do things on a big scale, then my diabetes will improve. (male, 37 years)

The information provided by the different health professionals was conflicting and confusing for half of the patients interviewed. Many found that each health professional instructed them differently about different aspects of their diabetes care. Many felt overwhelmed by the amount of information and the pace at which this information was delivered to them, especially those who have less English language proficiency. There was no health education follow up to supplement what had been provided during their first appointment.

I was taught about diabetes by the nurse when I was diagnosed but I could not remember what she taught me, it was one session when I was in the hospital. So many health people visited me, I don't know who. (male, 52 years)

There was one patient who thought there were advantages to multidisciplinary care and who had been given clear and consistent advice; however, he still found going to many professionals inconvenient. None of the patients interviewed were concerned about privacy when health professionals shared their health information between themselves.

Barriers to multidisciplinary care

Being referred to many health professionals was seen to dramatically increase health care costs which discouraged patients in following up with their health care professionals. Although the five funded allied health professional consultations provided under the Australian Medicare Team Care Arrangement (TCA) helped to make care affordable, five visits were often not sufficient to meet the complex health needs of patients with chronic diseases and multiple co-morbidities.

Follow-up visits are also prohibitive to some patients. For example, one patient removed his own dressing to minimise the cost of follow up.

The hospital told me the date to go and change the bandage. When we went there they charged me \$150

to take out the bandage, only the bandage but not the stitch and when I came back I tried to open by myself because I did not have the money because they wanted a fee to just open the bandage. Then I went back again to take for the stitches and I had to pay money for the stitch. (male, 44 years)

In addition to socioeconomic factors, cultural issues, such as food preferences, were also seen as issues not addressed by health professionals. When this patient was asked why she didn't want to be referred to a dietician, her carer answered that

We eat more spices and then the dietitian recommends something with less salt, less sugar, less fruits then it becomes difficult. (carer of female patient, 80 years)

Co-morbidities as barriers

While patients with multiple co-morbidities acknowledged the need for specialised allied health support services for their diabetes care, they found it harder to participate in team care because of the difficulties in juggling priorities, not only their medical needs but also more pressing socioeconomic and cultural concerns. Some of the patients felt that their co-morbid conditions were being dealt with by different health professionals rather than a multi-professional team managing them as one patient who has all the conditions.

My diabetes doctor checks my blood sugar and my eye doctor looks at my eyes and scheduled me for laser treatment and my heart doctor gives me tablets and my arthritis doctor gives me steroid shots. I feel like many diseases and each piece of me is being treated by different doctors. Too many doctors. (female, 67 years)

Physical co-morbidities present as a challenge to participation in integrated care, which may be seen as non-compliance to follow up. One of the patients interviewed had problems with urinary incontinence and refrained from drinking water from the night before her appointment.

I have to stop drinking water from midnight till I come back from the appointment because I don't want to have to look for toilets everywhere. (female, 50 years)

She often felt dehydrated and unwell when she finally returned home and this added to the difficulties she faced attending multiple appointments.

Depression was a common co-morbidity among the patients interviewed.

To be honest I am sick of it. I had the needles and sometimes they hurt and sometimes they don't. I just go through the motions now and just talking about it now gets me so depressed. (male, 42 years)

Some said that they 'could not be bothered' (male, 52 years) to take control of their care and balancing co-morbidities led to more confusion and inaction. An example is this patient who was diagnosed as having diabetes but had multiple issues with drug addiction and gambling.

It is very difficult for me trying to look at what I should deal with first. I find one thing is hard to deal with when I should be dealing with all of them you know. Even though I should be taking one at a time it is very confusing which one I should take. Many times I feel like I should fall asleep and hope that I won't wake up. (male, 42 years)

Lack of support from health professionals

Patients also reported a poor understanding of their diabetes and self-management. They felt that there was lack of support from health professionals for health education and need for more information, for follow-up care and for setting goals for their diabetes control, making the motivation to self-manage very low. While patients found the diabetes education provided by the GP or diabetes educator during the early part of diagnosis useful, many had little recollection of the information given. There was little follow up to reinforce learning and to provide guidance.

Some of the patients who were referred to community health diabetes education programs and support groups were disinclined to participate because of their poor English language ability.

My English is not so good and so I don't like attending groups or going to consult many health people. (female, 67 years)

One of the patients was reluctant to use the interpreter service during medical consultations because of privacy reasons.

Lack of communication among health professionals

Another patient was seen as non-compliant because he failed to follow up with his specialists and GP for treatment for a diabetic foot ulcer. He said that he had neither transport nor the financial resources to go to the specialist and his GP no longer bulk billed which discouraged follow up. He was eventually referred to community health for wound care at home after discharge. Over time he noticed inconsistencies between the community health nurses in the method of wound dressing saying,

They don't seem to communicate with each other. (male, 52 years)

The health professionals involved in his care, including his regular GP, the staff specialist from the local hospital and the community health team confirmed that communications between them had been through referral letters carried by the patient as he journeyed through the fragmented health system. There was no formal case discussion among them regarding his care, even though the treatment for his diabetic leg ulcer had been ongoing for 18 months. This highlights the lack of communication between health professionals in the care of patients with complex

health needs which may be a factor in patients not receiving integrated or coordinated care. All the patients interviewed stated that they acted as the messenger between the different health professionals involved in their care, particularly if the care spanned the primary and tertiary levels. This was often through referral letters they carried to their consultations and the verbal medical history they related. They did not think that there was direct communication between their health providers.

Carer as coordinator

The presence of a dedicated care coordinator like a family member seemed to be an important resource that enhanced integration of care for one patient. This patient had very minimal English language ability but had a daughter who coordinated her care. The daughter took her to her many health appointments, liaised between the patient and the health professionals and monitored her condition at home. Her numerous specialist appointments were tracked and followed because her carer was actively navigating her referral pathways on her behalf. The downside of this arrangement was the carer did not necessarily understand the importance of the role of the allied health professionals and the potential benefits from an appointment. When the carer was asked whether referral to a dietician would improve her mother's care, she said,

We don't know because in her situation she is OK. Since her diabetes is under control by herself. We don't see the need to go for those sorts of visits. (carer of female patient, 80 years)

Discussion

The multi-disciplinary care experienced by the patients in this study was perceived as poorly coordinated, with dysfunctional communication among the members of the 'team'. This may be a reason for minimal engagement by the patients. Merely adding health professionals to the management mix does not equate to the idealised vision of integrated care for these patients. A proactive health team that will motivate, inform, activate and prepare patients will be of benefit but must be supported by a collaborative service organisation and delivery backed by appropriate and adequate resources and policies (Kirby *et al.* 2008; Schattner *et al.* 2008; Shortus *et al.* 2007).

When patients were referred to different health professionals, the logistics of scheduling and attending various appointments, finding time, transport and support to get there, re-telling the medical history and remembering treatment were burdensome. Information received was found to be conflicting in some cases and often the quantity of information received was deemed too much and overwhelming by some patients. Integrated care appears to be a middle class concept with little applicability to those from disadvantaged backgrounds or those with several chronic conditions. Patients with inadequate health literacy are generally those with fewer economic resources, have low English proficiency, are older with lower levels of basic literacy skills (Kirby *et al.* 2012; Schillinger *et al.* 2002). They are the ones who are less likely to independently navigate the health system or have the confidence to work with health professionals in taking up health-promoting behaviours (Kirby *et al.* 2010).

Health professionals tended to focus on their own area of expertise despite recognising that good diabetes outcomes need well-integrated multidisciplinary care. The role of the care coordinator is not clearly defined or understood by the patients. Although many of the patients interviewed recognised that their GP was the coordinator of their care, they also claimed that there was little communication and coordination between health care providers except through referral letters that they often delivered themselves. In a study by Gardner and Sibthorpe, the hospital, community and consumer groups questioned the capacity of the GP to do the duties and responsibilities of care coordinator, citing their lack of time, training, communication skills and interest to be so (Gardner and Sibthorpe 2002). In the hope of improving care for patients with chronic conditions, the NSW Ministry of Health recently implemented the Connecting Care (chronic disease management) program with specialised primary health care nurses coordinating the care while recognising the GP as the main medical care provider. The role of the care coordinator is to liaise between patients and health care providers, empowering patients with self-management skills, follow-up appointments and monitor treatment compliance.

Self-management skills in patients with type 2 diabetes

While having a supportive family can alleviate many of the tasks needed to organise and manage day to day care, (Fisher and Weihs 2000; Procter *et al.* 2001), not all patients have this resource and privilege. Many health professionals missed the opportunity to motivate patients to self-manage and support was lacking in activating these patients to be proactive in managing their diabetes. Such support could have been taking more time to explain the disease processes and subsequent complications and in setting therapeutic goals. Reinforced in this study is the finding that lack of basic understanding of the disease process and progression hinders patients from being involved in their care. Multidisciplinary intensive diabetes education is recognised as effective in improving glycaemic control and quality of life (Keers *et al.* 2005). However, patients with low functional health literacy are challenged by the technicality, amount of information being given within hurried consultations that are often only minutes in duration (Schillinger *et al.* 2004). Patients need time to understand the disease process and develop the skills and confidence to manage their health (Coulter and Ellins 2007). This requires tailored, active, long-term support and regular follow up from health professionals (Schillinger *et al.* 2003). Although health professionals are confident in their ability to educate patients, providing practical ways to help change patients' behaviours is more challenging (Chin *et al.* 2001). Chronic disease requires long-term management and goal-setting; action-planning and problem-solving are essential to improve patient self-efficacy (Wagner *et al.* 2001). Patients often claimed to have had no help from the health professionals in these areas where, if the help had been provided, assistance could have improved the process of care and patient outcomes (Dennis *et al.* 2008). Working in collaboration with community health providers to increase patient engagement in the community (Dennis *et al.* 2008; Norris *et al.* 2006; Portillo and Waters 2004) may maximise the impact of specialist community health

providers in tailoring culturally and clinically appropriate care (Metghalchi *et al.* 2008).

Patient access to services

Our findings reflected those of Kirby *et al.* (2010), who found that for patients, in addition to their medical conditions, co-morbidities and adverse socioeconomic conditions, access issues such as transport, location of services and waiting times are important factors that increase emergency department presentations and act as barriers in their participation in multidisciplinary care (Kirby *et al.* 2010). A single front office reception and entry point for patients, a flexible appointment system with timely reminders and follow up, and a well-appointed, centrally located multiprofessional practice are some of the services that will help shape a 'prepared' patient, particularly those with complex needs. A dedicated care coordinator to assist in navigating the care pathways may provide the best conduit between patients and health professionals.

Understanding the contextual background of patients is important in tailoring care to achieve optimum health outcomes (Weiner *et al.* 2005). For example, one patient interviewed was not able to comply with follow up, diet and medication schedules because of work shifts. Whole-of-person care has also been emphasised as an essential element of effective communication between services and should include family and community as part of the health care team (Weiner *et al.* 2005). Accommodation of the needs of patients by health services is important to improve patient engagement and encourage access to services.

The effect of co-morbidities in patient management

As demonstrated in our patients, those with multiple co-morbid conditions often find it difficult to juggle many health care appointments and needs (Bayliss *et al.* 2003; Kerr *et al.* 2007). This adds to the burden and complexity of self-management for patients who are already disadvantaged by low self-efficacy, low English language skills and a host of socioeconomic issues. Whole-of-patient care should consider the impact of co-morbidities on the patient. Patients with multiple co-morbidities find it more convenient to use the ED for outpatient consultation than their GP and the ambulance is an easy means of transport to the hospital where technical and diagnostic support means less waiting time. Presenting to ED is also seen as a stronger validation of the patient's sick role compared with consulting the GP (Kirby *et al.* 2010; Lowthian *et al.* 2012). However, the EDs are the more expensive option.

Depression is a common co-morbid condition among the patients interviewed and is known to be associated with higher medical care utilisation (Goldney *et al.* 2004). Addressing mental health issues is as important in the management process as treating physical symptoms. Patients with depression tend to magnify physical symptoms and are less likely to self-manage or adhere to therapeutic regimens (Ciechanowski *et al.* 2000). This increases the likelihood of hospital admissions.

Limitations of the study

A relatively low number of patients from one district hospital participated. However, qualitatively it appears to represent an ethnically diverse and low socioeconomic status population.

While patients with very poor English language skills were excluded from the study, we can still conclude that culturally and linguistically diverse and socioeconomically disadvantaged patients have special needs that must be considered in any proposed integrated care system.

Conclusion

Our study showed that patients did not perceive their diabetes care as integrated. Their care appeared to be disorganised and fragmented. The patients were confused and overwhelmed by the processes involved. Personal biophysical and psychosocial issues, such as poor English language skills, transportation, socioeconomic issues and competing priorities of co-morbidities, are important barriers for patients, compounding their difficulties in participating in their health care. The poorly coordinated and 'un-integrated' services made these barriers even more challenging. Further research is needed to better understand how multi-disciplinary team care can be integrated and coordinated more effectively, informed by the key problem areas identified by patients in this study. Addressing important issues such as high cost of care, cultural barriers, lack of coordinators and lack of support for self-management may improve the clinical management as well as the integrated care of diabetes in this instance. The onus is on the health service to organise and deliver multidisciplinary care that is perceived by patients and their carers as 'integrated' and 'coordinated'.

Conflicts of interest

None declared.

Acknowledgements

D. M. received a Researcher Development Program Fellowship from the PHCRED program to undertake this work. H-Y. C. is supported by the Main Roads Western Australia Research Fellowship. Thanks to Charmaine Rodricks for transcription and technical support. This paper honours the memory of Jeremy Bunker, whose insightful comments were invaluable to this program of work.

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