

Culturally and linguistically diverse patients' views of multimorbidity and general practice care

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ABSTRACT

INTRODUCTION: It is recognised that patients who are culturally and linguistically diverse (CALD) have challenges in accessing health care and understanding health advice or instructions. Those with multimorbidity (MM) are likely to have additional difficulties. In New Zealand, little is known about how this patient group view their health and general practice health care. This study examined the views of multimorbid CALD patients about MM and the health care available in a Very Low Cost Access general practice.

METHODS: This qualitative study recruited Samoan, Cook Island Māori, and Cambodian patients with diabetes and more than three other long-term conditions. Two individual interviews and two language-specific focus groups were undertaken to yield themes representing the experience of these CALD patients with MM.

FINDINGS: Participants described MM as having considerable impact on their life. They reported feeling responsible for supporting their own health and many detailed self-management techniques. However, they also expressed confusion, lack of information and limited understanding of MM, in particular about managing medication. Not all patients were aware of the range of available general practice services and some described difficulties in accessing general practice care.

CONCLUSION: Despite being motivated to self-manage, this patient group report challenges in understanding their conditions and how to manage them, which may also be influenced by health beliefs. Available general practice services are not well known by CALD patients with MM. There is likely to be value in developing a specific structured, yet patient-centred, model of care for this group of patients.

KEYWORDS: Access to health care; ethnic groups; focus groups; general practice; health literacy; self care

Introduction

International studies show that patients who are culturally and linguistically diverse (CALD) may receive lower quality care with regard to access, screening and communication.¹ Culture, language and ethnicity influence beliefs about health and illness and it is known that this impacts on health-seeking behaviour, health literacy, health expectations and patient self-management.^{2,3} With regard to patient self-management, it cannot be assumed that people of different ethnicities will want to self-manage.³

To date, little is known about how CALD patients experience multimorbidity (MM) and their views of care delivery in New Zealand (NZ) general practice. MM is generally accepted to mean the coexistence of two or more significant long-term conditions (LTCs), where none is central,⁴ and exacerbated by other functional morbidity (e.g. pain, falls). In NZ, the Ministry of Health Care Plus programme has enrolled patients with two or more LTCs, but the programme has not systematically identified the MM subgroup with arguably greater and more complex health care and self-management needs, and poorer quality of life.⁵

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Patients with MM report that managing several conditions can take two to three hours a day and that there are significant unfunded health care costs.⁶ They find it difficult to self-manage several, equally contributing conditions, take multiple medications and reconcile different treatment plans often developed by different clinicians.^{7,8} This is particularly so when patients are CALD, with the additional challenges of language translation and health literacy, lack of tailored resources, and more limited health service navigation skills.⁹

MM has rapidly increased in the past 20 years, and is predicted to increase further.^{10,11} Estimates of MM prevalence vary according to definition, with 51% of adults with LTCs in NZ thought to have MM.¹² These patients are often in their middle years and in Australia 40% of people with MM are less than 60 years of age.¹³ Multimorbidity more frequently occurs in disadvantaged groups and with greater severity, and this is likely to include CALD populations.^{14,15} Community-based generalist health care has been proposed as more appropriate than hospital specialist care for people with MM.¹⁶

To date, MM research has been largely undertaken from a clinician rather than a patient perspective. It does not appear that any NZ studies on MM have focused on the experience of patients who are CALD.

This study was based in a Very Low Cost Access (VLCA) general practice in Wellington, NZ. The Ministry of Health VLCA scheme provides specific funding support for general practices with enrolled populations of 50% or more high-needs patients (Māori, Pacific or New Zealand Deprivation Index quintile 5), if the practice maintains their patient fees at specified reduced levels. The practice manages a complex population with high levels of deprivation and a diverse ethnic mix. Professional and family interpreters are frequently used in consultations.¹⁷ To meet the needs of this diverse population, the practice offers a variety of service models, including community outreach, general practitioner (GP) and practice nurse (PN) team care, onsite specialist input, and on-the-day GP appointments.

WHAT GAP THIS FILLS

What we already know: Patients who are culturally and linguistically diverse have recognised challenges in accessing suitable health care and understanding information and instructions. There is likely to be an additional burden associated with having multimorbidities.

What this study adds: Patients with multimorbidity who are culturally and linguistically diverse have particular challenges, including a lack of understanding about multimorbidity, how conditions influence each other, and the use of medication. These challenges, together with existing health beliefs and family and work influences, impact on self-management practices. In general practice, a structured, yet patient-centred model of multimorbidity care for patients who are culturally and linguistically diverse is likely to be advantageous.

This study aimed to examine the views of multimorbid CALD patients about MM and the health care available in a VLCA general practice. It is part of a wider study also exploring the views of the health professionals caring for this patient group.

Methods

This study using qualitative methods was designed to yield themes representing the experience of CALD patients with MM.^{18,19} The general practice partnered with staff at the University of Otago Wellington through a summer studentship to undertake the study. Ethical approval was granted by the University of Otago Ethics Committee (Ref. H12/054).

Recruitment

As there was no specific general practice register of those who meet the criteria for MM, patients were recruited from a subgroup of those on the diabetes register aged between 45 and 64 years, who had more than three other LTCs. The research team deliberately set this higher inclusion criteria than the accepted MM definition to ensure that recruitment was of CALD patients with significant MM. An additional emphasis was placed on recruiting patients whose spoken English was known by the practice staff to be limited.

Data collection

Focus groups with interpreters were planned and a purposeful recruitment approach targeted the

larger CALD groups at the practice, including Samoan, Cambodian and Assyrian peoples. A Pacific Navigator (a role designed to enable Pacific patients and family to access health services to improve health and wellbeing) individually approached and recruited a Cook Island Māori patient and Samoan patients, and similarly, a Cambodian interpreter approached and recruited Cambodian patients. Planned Assyrian interviews were unable to proceed because of recruiter illness.

Trained interpreters each facilitated language-specific focus groups (one in the Samoan language, one in the Cambodian language) contemporaneously translating patients' answers into English throughout the focus groups. The summer student researcher facilitated individual interviews in English with one Samoan and one Cook Island Māori patient and also attended the ethnicity-specific focus groups and recorded field notes.

Individual patient interviews were undertaken in the patients' homes and focus groups at a church near the general practice which is regularly used for health promotion activities. Interviews ranged between 15 and 80 minutes and each was audio-recorded.

An interview question guide was followed, but in accordance with guidance for running language-specific focus groups,²⁰ the interpreters were asked to use alternative language/terms to convey the meaning of the interview question. Interview questions included the experience/impact of having MM, beliefs about health and MM, and perceptions of general practice care received and possible improvements in care.

Analysis

A pragmatic approach to transcription of audio-recordings was undertaken, with relevant

sections transcribed from each interview (e.g. English language portions of non-English focus groups). Audio-recordings and transcripts were then independently reviewed and the transcripts were manually coded by the student researcher (SG) and then by a supervisor (EM), identifying the topics, ideas, views and concerns until common categories emerged.²¹ These categories were then discussed with another supervisor (PH), divergent views resolved and final agreement reached on the themes and subthemes.

Quotations that best represented the themes and subthemes from the data were then chosen for inclusion in this paper.

Findings

Ten CALD patients (five males and five females) with MM (plus one female partner) took part in either individual or interpreted focus group interviews (see Table 1). No other demographic or specific LTC information was requested from the patients.

Patients particularly wanted to discuss their experience of having MM, including challenges and self-management strategies, and there was less discussion about general practice care. An inductive analysis revealed the following five key themes:

1. confusion and lack of understanding
2. health beliefs
3. the impact of MM
4. self-care and self-management skills, and
5. care by the general practice.

Confusion and lack of understanding

Patients described a lack of understanding or confusion about MM. They reported feeling that health professionals didn't always clearly explain their conditions to them. This resulted in the

Table 1. Patient interviews: type of interview, ethnicity, gender

Interviews	No. of people	Gender
Samoan language focus group—interpreter used	4	3 males, 1 female
Cambodian language focus group—interpreter used	5	1 male, 4 females including 1 female partner
Cook Island Māori individual interview	1	1 male
Samoan individual interview	1	1 female

patient not always appreciating that they had a range of conditions, how each affected their body, and how the conditions may interact.

...and I ask the doctor, 'What's diabetes?' Sugar is high ... even today I still puzzled because they are not explained properly how high ... the sugar [is]. All they say is 'diabetes'. (Samoan language focus group, patient #3)

Patients also commented that health professionals did not always have enough time to explain and educate.

For my medication... 'cause the doctor don't have time to explain things properly... I collect the information from the pharmacy... (Samoan, individual interview)

Patients noted that staff frequently didn't use language-specific information resources.

I still hope that someone will explain this or write a book about it. To explain how high your sugar or how high your sugar or blood lines could be. I wish they could write in Samoan too, so we could all read it. And... tell us what sort of food we can have. (Samoan language focus group, patient #4)

Health beliefs

Some patients talked of specific beliefs about their illnesses and how this affected their understanding of what to do about them. This included their beliefs about the functions of the body (e.g. sweating cures disease) and actions to improve symptoms (e.g. fasting to improve blood sugars).

I... sweat it [out] so that would help [me get better]. (Cambodian language focus group, patient #4)

The sugar level's quite high. I'll eat something then and then I'll do the test ...my sugar and then it's gone up[then] if I 'fast' for two days that's the sugar levels will drop down. (Samoan language focus group, patient #2)

Cambodian patients spoke of 'shaking', (seemingly meaning hypoglycaemia), and the measures they took to address this.

I wake up shaking and don't feel well... I just go straight to rice pot and have some rice and I just [eat] mouthfuls and go back to sleep... (Cambodian language focus group, patient #1)

Effects of multimorbidity on health, functional ability and work

Patients named their conditions, gave physiological descriptions of what they understood was happening in their body and described the impact on function.

I've got heart disease... congestive heart failure... I got diabetes... a bit of emphysema... now they're worried about my kidneys. (Cook Island Māori, individual interview)

I'm a sick person. About 1980 the doctor told me I've got diabetes... from that time I was on medication. [In] 1998 when I went to Samoa I didn't do pills... some of the veins or blood vessels had burst in my eyes... also my kidneys were also affected at that time. (Samoan language focus group, patient #3)

The patients went on to describe how MM affected their daily lives.

I get really careful of what I do and what I eat and the work I do at work, and the work I do at home. I sort of balance those out 'cause if I get really, really tired sometimes I can't even walk up the stairs. (Samoan individual interview)

For many, taking multiple medications every day was a considerable challenge, especially in terms of understanding what each medication was being taken for and why. It was clear that prescribed medication was not always being taken as it was intended.

... They just gives pills and we take it [and] they explain this and that and this pill controls this and that pill controls this. So to me [it's] still not very, very clear how they [the medicines] do this thing [treat the condition]. (Samoan language focus group, patient #3)

I got some medication to take but I can't take too much medication because my stomach will get upset if I take a lot of medication. So I didn't take

it and I still have the pain. (Cambodian language focus group, patient #3)

Self-care and self-management

Patients acknowledged during discussion that they had a key role to play in their own care. They reported feeling responsible for undertaking actions to support their health.

I know the doctor can only give me advice and follow up. But me [has] to help me... the doer is me ... (Cambodian language focus group, patient #4)

Given that all the patients participating in the study had diabetes, it was not surprising that participants talked extensively about challenges with diet management.

So yeah if you can... control your diet, manage what you eat. (Cook Island Māori, individual interview)

Although I try hard to have a regular meal at a regular time but I can't [always] do that one because my husband's condition and also my work... I'm busy at work as well, and so I try. (Cambodian language focus group, patient #2)

I still get told by [the general practice] that I need to lose more [weight]. ... I have no idea of how to stop eating the food. (Samoan, individual interview)

Other self-care strategies were also reported by participants as important.

I actually try and get into exercise. I have joined a gym sometimes but I find sometimes my work, my hours of work does not allow me to do that so... I have just bought a total gym to do it at home. (Samoan, individual interview)

Patients discussed the impact of paid employment on their health and also on accessing health care. Having multiple jobs and undertaking shift work was not uncommon amongst participants and created additional challenges.

I was able to do the work... actually I had two jobs... but as the years goes by the diabetes is not controlling properly and I had a lot of problems trying to control it... gets in the way my work. (Samoan, individual interview)

...Cause I go to work in the morning at 6 [a.m.] finish at 9 [a.m.] and come home, have a breakfast and then ... go to sleep for two hours and then I go back to work. (Samoan language focus group, patient #3)

I didn't turn up [for an appointment]. I was very busy at work... but like I said I haven't been seeing the doctor lately. (Samoan language focus group, patient #1)

The role of community and family featured frequently in discussion and patients expected that family would be involved in care. Often family support was a positive influence on self-management, but not always. Cultural expectations created challenges especially around diet.

[In] the Samoan community when it's some Sunday feast everybody comes with a huge pile of food. It's what we share amongst with the community so it's hard to reject those type of function ... huge amounts of food will be served at that day ... some people they taking drugs for their dietetic [diabetes] but they can't ... have that much food... (Samoan language focus group, patient #1)

Care by the general practice

Patients commented on the ease or difficulty of accessing general practice care, as well as how care was given. Some appreciated the GP/PN model of team care and some preferred GP-only care. Others acknowledged the input of the specialist doctor. A few mentioned having the support of the community outreach staff member.

...Cause every three months they check us and the nurse if there is anything that she's not sure, she'll always send the doctor...they work together so well. (Cambodian language focus group, patient #1)

... the specialist for the kidneys, the specialist for my eyes... there's also a specialist or doctor that looks ... after my foot. They all come in to my GP. (Samoan language focus group, patient #2)

I can go to [the clinic] and see the nurse but I prefer to come and see my own doctor [GP]. (Samoan language focus group, patient #1)

Patients suggested strategies to improve care, including wanting to book on-the-day

appointments with a specific GP and reducing the length of time in the waiting room before being seen.

I rung for a doctor's [GP] appointment and the nurse answered the phone and said they are fully booked and I said I really need to see a [specific] doctor and that's the only answer [fully booked] they gave me. (Samoan language focus group, patient #2)

Some people come with appointments at 10 o'clock and you end up wait[ing] for half an hour or 45 minutes ... I'd rather [be] 15 minute late but not half an hour or 45. (Samoan language focus group, patient #4)

Discussion

Internationally there is an increasing focus on the experience and care of those with MM, particularly care delivered in general practice. However, little is known about the experience of multimorbid patients who are CALD. In this study, the use of interpreters to facilitate focus groups was a key to ensuring patients understood the nuances of the interview questions and could respond in their own language, which then could be translated into English. Although this slowed down the focus group process, it appeared to allow other participants time to think about their responses, and all freely participated.

Patients talked about a lack of understanding of MM, particularly with regard to the interplay between conditions and also the challenge of managing the treatments. Managing complicated medication regimens was frequently mentioned as a challenge, including knowing which medication was for what condition, how medications worked and what to do about side effects. This lack of understanding about medications resulted in concern and anxiety, and for some it seemed to result in a lack of medication concordance. This treatment burden is a known result of MM, but may be exacerbated when patients have additional language or literacy barriers.²²

Patients' individual health beliefs also added to the general lack of understanding of MM, with the example of needing to 'fast' to bring down blood sugars having potentially significant consequences if the patient was on diabetes medica-

tion. When taken together, lack of understanding and health beliefs impacted on health literacy.²³ Similarly to findings of other studies, patients wanted more opportunities, methods and time²⁴ for information transfer, patient education and self-management support, and mentioned a desire for translated resources.²⁵

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Even though language-specific written information was mentioned, none of the patients suggested the role/value/use of a written care plan as a tool to support self-management. Although these have proven effective in dominant-language populations, the use of written care plans does not appear to have been trialled in CALD populations and would require considered implementation (e.g. translation, use of interpreters, appointment length). Mangin et al. endorse the use of care plans, individualised to the patient's particular MM complexity, and clearly identifying priorities for care.¹⁶ In NZ, the use of an electronic shared care plan with a patient portal has been shown to facilitate interdisciplinary, cross-sectorial and patient communication, with potential for improved care.²⁶

Given that patients spoke of their desire for family involvement and family support with self-management, further research is needed to understand this concept in relation to MM in CALD populations.⁹ Boyd and Fortin have advocated the need for research looking at 'optimal ways to engage family members in the care of people with multimorbidity'.⁴

Although participants in this study had at least three LTCs in addition to diabetes, they particularly focused on diabetes and the limitations or restrictions it created. It has been suggested that patients prioritise symptomatic conditions ahead of asymptomatic conditions because the former exacerbates functional limitations and/

or causes financial stress.²⁷ The prioritisation of diabetes in this study contrasts with the findings of Bower et al.⁷ where patients did not highlight diabetes, as it was felt less important than other conditions. This may reflect the severity of the diabetes in this study, with many patients requiring specialist input. There was also considerable discussion by participants about the impact of employment on diabetes management, particularly shift-work on meal times and timing of taking medication. It is clear that the need to be healthy enough to work and to be paid was of considerable concern, highlighting the generally low socioeconomic status of this population.

In contrast to an Australian study by Sav et al.,²² the cost of general practice fees was not frequently mentioned as a barrier to care, perhaps reflecting the VLCA payment structure. However, when mentioned as an issue (Cambodian patients), GP/PN team care was preferred, as the PN provided 'no-charge care' and the GP was called if required (medical assessment, medication prescription). Despite this, patients appeared to have a poor understanding of the roles of PNs (apart from taking clinical measurements and not charging for services). In contrast, patients acknowledged the role of dietitians for diet management, pharmacists for their understanding of complex medications, and social workers for broader health and social issues. Pacific patients appreciated the assistance of the community outreach staff member. However, although various additional services are available in this VLCA general practice, including combinations of disciplines and modes of delivery, these were not often talked about in the interviews. Research has shown that GP endorsement of other disciplines' roles and team care can lead to greater acceptance by patients.²⁸ By routinely discussing with or specifically offering these services to CALD patients with MM, there is an opportunity to increase patient-centred care.

Patients acknowledged the importance of good relationships with staff and nearly all described positive interactions. However, these positive clinician-patient relationships ideally should also be supported by a structured model of patient-centred, interdisciplinary MM care.²⁹ This more systematic approach to MM care may be especially important for CALD and/or disadvantaged

populations,³⁰ as it is recognised that 'determinants influence the effectiveness of specific clinical recommendations'.³¹ In NZ, despite capped numbers, Care Plus funding has enabled general practice to increase regular attendance for some patients with two or more LTCs, although arguably this has not targeted the higher-needs subgroup with MM, and particularly those who are CALD. The more recent flexible approach to Care Plus funding via primary health organisations enables general practices to use a range of service delivery models for LTC care.

Limitations

This study was conducted in one VLCA general practice with a diverse CALD population. Due to time and resource constraints, data saturation cannot be claimed as not all CALD subgroups were recruited. However, the study purposefully recruited patients with MM who are CALD and used non-English-language-specific focus groups with interpreters as facilitators; this method does not seem to have been used to date in MM research with CALD patients in NZ. A further strength was the number of male participants, as males can be difficult to recruit for such studies.

In the absence of an MM register, those on the diabetes register with diabetes and more than three concurrent LTCs were used as a proxy. This may have led to inclusion of some patients with diabetes as an index condition rather than an equally contributing condition.

Not all qualitative data were fully transcribed; however, all data were independently reviewed by two researchers before theme agreement.

Final comments

Culturally and linguistically diverse patients with MM expressed a range of views, priorities and challenges, including need for more information, education, involvement of family and clarification of health beliefs. This suggests a greater understanding is needed to support CALD patients with MM. A patient-centred approach, systematically offering additional available services and with increased education and information support to patients and families is likely to be advantageous.

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COMPETING INTERESTS

None declared.