A walking stick in one hand and a chainsaw in the other: patients' perspectives of living with multimorbidity

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ABSTRACT

AIMS: Multimorbidity is common, yet there are major gaps in research, particularly among younger and indigenous populations. This research aimed to understand patients' perspectives of living with multimorbidity.

METHODS: A qualitative study of 61 people living with multimorbidity, 27 of whom were Māori and a third aged under 65, from urban and rural regions in New Zealand. Six focus groups and 14 interviews were conducted, recorded, transcribed and analysed.

RESULTS: For many participants, living with multimorbidity disrupted their 'normal' lives, posing challenges in everyday activities such as eating and toileting, working and managing medications. Dealing with the health system posed challenges such as accessing appointments and having enough time in consultations. Cultural competency, good communication and continuity of care from healthcare providers were all valued. Participants had many recommendations to improve management, including a professional single point of contact to coordinate all specialist care.

CONCLUSIONS: Living with multimorbidity is often challenging requiring people to manage their conditions while continuing to live their lives. This research suggests changes are needed in the health system in New Zealand and elsewhere to better manage multimorbidity thus improving patient's lives and reducing costs to the health sector and wider society.

Multimorbidity, the coexistence of two or more health conditions,[1] is a common and growing problem worldwide.[2] While the risk of multimorbidity is higher in those aged 65 years and older, a study of over two million people in Scotland found that the absolute number of those affected was greater in those under 65.[3] Multimorbidity is more frequent and occurs earlier among those living in socioeconomic deprivation, and disproportionately impacts indigenous people.[3,4] People with multimorbidity are the major users of health services, accounting for around two-thirds of healthcare spending.[5] There is a large body of literature documenting the clear associations between multimorbidity and increased risk of hospitalisation, adverse effects of treatment, high healthcare costs, reduced quality of life and higher mortality.[3,5–9] Despite this, there are major gaps in research relating to nearly all aspects of multimorbidity, particularly among younger and indigenous populations.

Research on multimorbidity from a patient perspective has been called for[10,11] and is emerging.[12,13] Patients have an important role in managing their own health needs; however, the 'work' for patients associated with chronic illness management increases significantly with increasing comorbidities, and may exceed the patient's capacity to cope.[3,14] This can be even more challenging when patients' priorities do not align with those of their doctor, with a recent study finding the main healthcare priority of the patient was not represented in the top three priorities of their physician. This discordance increased with higher levels of patient complexity.[14,15] It is becoming widely recognised that greater coordination of person-centred health services is needed, especially for patients with multimorbidity.[16] Increasing tailored information, education and training, as well as community support, should not be overlooked for this population, with studies suggesting better outcomes for those individuals with the skills, knowledge and confidence to manage their own conditions.[17] A 2010 framework,[18] alongside a more recent education and training programme,[19] suggests a need for more research and an improved evidence base for interventions to benefit people with multiple chronic conditions. This is supported by a recent Cochrane Review, which found only a small number of trials looking at interventions to improve outcomes for people with multimorbidity with mixed results.[1] This research sought to understand patients' perspectives on living with multimorbidity, their views on healthcare and support and what interventions might improve their lives.

The research was conducted in New Zealand where primary healthcare, the gateway to the health system, is largely subsidised by the government, though most adult patients make part-payments for consultations. Secondary services are provided at no direct cost to patients. While pharmaceuticals are heavily subsidized, there are still part-charges for prescriptions. Additional subsidies are available for primary care and pharmaceuticals for those with low and middle incomes, disabilities or high healthcare use.[20]

Methods

This qualitative study took a phenomenological perspective recording and analysing multimorbidity from patients' perspectives.[21] We used a mix of focus groups (6) and interviews (14) to gather data from a large strategic sample, capturing various perspectives from a range of patients with multimorbidity. Focus groups enabled the large sample while interviews included hard-to-reach participants.

Participants

Participants with two or more long-term conditions were recruited through primary healthcare organisations from three regions in New Zealand, from urban and rural locations and a range of socioeconomic and ethnic groups.

A total of 61 people participated in this study, 14 in interviews and 47 in focus groups, 27 of whom were Māori (indigenous). Half of the participants were living with four or more conditions. Similar numbers of men and women participated. Over a third were aged under 65 years. For participant demographics, see Table 1.

Fourteen participants were unable to attend the focus groups due to poor health, difficulty accessing focus groups or availability. They were interviewed individually either at home or work. The focus groups and interviews were audio-recorded and field notes taken. Focus groups lasted ≈90 min and interviews ≈60 min.

Table 1: Participant demographics.

Demographic	Number (%)
Gender (n=61)	
Women	28 (46%)
Men	33 (54%)
Age groups	
Under 50	5 (8%)
51–64	17 (28%)
65–74	20 (33%)
75+	19 (31%)
Location	
Urban	42 (69%)
Rural	19 (31%)
Number of conditions	
2	13 (21%)
3	17 (28%)
4+	31 (51%)
Ethnicity	
Māori	27 (44%)
Pacific	12 (20%)
NZ European	21 (34%)
Other	1 (2%)

Data collection

A semi-structured interview schedule was developed based on findings from previous research[9,22] and with input from both clinical and community Māori (CMOG) advisory groups. Participants were asked about the impact of multimorbidity on their lives, what healthcare and other support they had received, what was positive about it and where it could be improved. At least two researchers participated in each focus group. Audio-recordings were made and transcribed verbatim.

Data analysis

Transcripts were entered into N-Vivo 10. Following careful reading by the research team, thematic analysis was used to identify emergent themes within the text and transcripts coded accordingly. Cross comparison occurred until a coding hierarchy was developed outlining key themes and subthemes within the data. Data on key themes appeared to reach saturation. Initial findings were reviewed by CMOG and were then discussed with the research team until a consensus was reached. Rigor was maintained by independent analysis and multiple coding, triangulation of data analysis and cross comparison of findings.

Ethics

Participants signed consent forms at the beginning of each focus group and interview. Participants agreed to keep the focus group discussions confidential. Transcriptions were numbered to guarantee confidentiality and anonymity. The project was approved by the University of Otago Health Ethics Committee (H14/124)

Results

The results are presented according to the themes that emerged from the data. Participants' quotations are presented in Tables 2 and 3 and briefly in the text.

Living with multimorbidity

What is it like?

When participants were asked about their experience of living with multimorbidity, a wide range of responses were elicited. Some reported that their health conditions did not unduly affect their lives, but for others living with multimorbidity had "taken a lot of the joy of life". For many, they managed their conditions and life simultaneously with, as one man said, "a walking stick in one hand and a chainsaw in the other".

Disrupting normal life

For many, multimorbidity disrupted their 'normal' everyday life and participants frequently reported times when managing their conditions was a struggle. The challenges they faced covered many domains both within the home and outside, including eating, sleeping, toileting and mobility. Some participants reported that their conditions left them feeling fearful of being alone. Participants who worked faced particular challenges and used a range of approaches to address them, including altering their employment conditions (eg, reducing hours) and changing employment. Others stopped working or retired.

Even leaving the house was difficult for some. Many participants reported needing to pre-arrange medications and food requirements, check access to toileting facilities and assess environmental conditions (weather, stairs, safety and resting places) before going anywhere. Participants would also consider their physical ability to determine if they required additional assistance to undertake an activity (eg, a wheelchair).

Coping strategies

While a number of participants described long periods of denying their multimorbidity, others integrated multiple coping strategies into their lives. A positive attitude was important to many. As one person said, "my mantra is every day above ground is a great day". Learning to manage their conditions was important for the majority of participants, who felt their independence was vital.

Care and support

Nearly all participants reported the need for care and support to manage their long-term conditions and prevent further ill-health, identifying psychological, social, spiritual and physical care needs. Participants reported accessing care and support from an array of people, including family and friends, neighbours, the community, healthcare providers and agencies providing social support. Support was provided in a number of different ways, including emotional, financial and practical support such as transport, gardening and information on disease and treatment. Government support services were essential for many within the study; however, the majority of participants indicated that available services were never fully explained to them, and even if they were, seeking such help was often 'frustrating' with complex application processes.

Managing medications

Managing medications was one of the greatest challenges for nearly all participants. First, remembering to take medications was a key issue, and often a measure of how well people felt they managed their conditions. A number of participants spoke about strategies they used to aid memory, with maintaining a strict routine and taking medications at the same time everyday being mentioned most commonly. Other strategies included writing the medications down, putting medications in an obvious place, setting reminders or alarms and using tools such as 'pill boxes'. Those that used blister packs found them useful to aid memory; however, some participants stated they were not using them because of the additional cost or difficulty opening them. Some participants suggested that their medication became 'easier to forget' when they were 'feeling well'. Second, the number of medications being taken was problematic for many, with one participant saying they felt like a 'chemist shop' and another wishing to have 'one pill for everything'. Some were concerned with the interacting side-effects of their medications. Third, a number spoke about needing to forego basic needs in order to afford their medications.

Participants spoke of skipping medications, primarily due to side-effects and the subsequent disruption on their lives. For example, several participants reported not taking their diuretic when they knew they were leaving the house, as it caused them to be incontinent. Participants discussed stopping medication due to cost, with a few prioritising conditions based upon severity and paying for these medications first. Others stopped medications due to negative side-effects, a lack of understanding about their health conditions and/or their medications, and occasionally distrusting doctors. Some participants expressed the view that they knew themselves and their own bodies better than their health professional did, which resulted in increased self-management through 'trial and error' either with or without the support of a doctor.

The health system

Travel to appointments

Organising travel to healthcare appointments frequently posed logistical challenges for participants, which were often amplified for those living rurally. Participants who were able to drive reported how valuable this was. One participant reported that driving was 'essential' and helped them 'cope'. A small number of participants noted that ageing and their deteriorating health would eventually result in them not being able to drive, ultimately leading to reduced independence and ability to access healthcare.

Participants who were not able to drive often relied on family and friends or the ambulance service, public transport, taxis and drivers from community health providers. For example, one participant reported feeling 'panicked' when organising transport and concerned that she may have 'exhausted' her friends as a source of assistance. Some rural participants talked about the extended journey they faced when trying to access specialist care; at times a whole day's travel to attend a brief appointment. This was more likely to occur if using public transport options, which were reported as 'limited' and at times 'inconvenient'. Other factors such as heavy traffic, driving in unfamiliar areas, length of travel time, parking and the distance to travel from car-park to appointment venue were all raised as a source of frustration and anxiety for people.

Appointments

There were three main issues identified by participants in relation to appointments in primary and secondary care: timely access, provider continuity and duration. First, many participants expressed 'frustration' at having to wait for appointments in their local primary care practice. One person was advised to go to the hospital emergency services if they required medical assistance that day. Another participant was more philosophical, stating "you have to put up with it", and others mentioned that the lengthy waiting times experienced at local practices were only an issue before you were 'in the system'.

Second, continuity was valued; many participants spoke of their desire to see the same health professional each appointment so that the practitioner knew their medical and personal history. However, this often resulted in increased waiting time for appointments, which in an emergency situation was not an option for many.

Third, a number of participants reported that the time available in a consultation was insufficient. In New Zealand, standard primary care consultations are fifteen minutes. Participants regularly commented that this was not long enough to discuss their complex conditions and their concerns around treatment options. A number of participants spoke about needing to make two appointments if they had multiple concerns to discuss; however, for some this was not a viable option due to the additional cost.

Cultural competence

Māori and Pacific participants' reports of 'mainstream services' (as opposed to culturally specific services) were varied, from complimentary to concern regarding cultural competence. Many Māori participants described their desire for health providers to take a holistic approach, including focusing on spirituality when managing their health. A large number of these participants described using a range of traditional, complementary and alternative medicines and approaches. Some participants stated that cultural differences were the main reason for a poor communication and a lack of rapport with health providers.

Communication

Patient-practitioner communication, or a lack thereof, often influenced how participants managed their multimorbidity. Many participants noted the importance of receiving clear information, or as one person said, "explaining everything", regarding their conditions or medications. Being able to discuss treatment options with health providers and having a trusted practitioner to talk to were highly valued.

Participants frequently mentioned that 'feeling listened to' was a necessary component in patient-practitioner rapport. Some participants felt consultations were 'a waste of time' if their health provider did not appear to be fully engaged with them, for example if they were focused on their computer to write notes. Some participants suggested that at times practitioners dealt with them as an illness rather than as a 'whole person', resulting in a poor relationship.

Integration of care

Navigating through different departments within a seemingly 'siloed' healthcare system was difficult for participants. One participant said she "felt like a jigsaw cut up into pieces". Many spoke about needing to explain their conditions multiple times to different health professionals, and others were frustrated at the conflicting information about medication and treatment options. Many participants valued seeing the same health professional, especially in primary care, where many felt they no longer had a 'family doctor' who knew their personal medical history.

Recommended changes

Participants were asked what changes, if any, they would suggest to health and other services to best support people living with long-term illnesses.

Managing medications: It was suggested by a small number of participants that either subsidised or free blister packs or pharmacy filled pill boxes would be valuable. In one focus group there was support for a wallet-sized medication card recording patients' prescriptions to assist patients to accurately relay their medical information, especially in an emergency situation.

Travelling to appointments: A range of strategies were identified to address the challenge of travelling to appointments, including services being co-located in the community, healthcare appointments being scheduled at convenient times for people travelling from out of town and home-based care, eg, prescriptions being filled and delivered by the pharmacy.

Culturally responsive health workforce: Māori and Pacific participants reported the need for greater representation of Māori and Pacific health workers, with the majority suggesting the need for culturally specific services alongside cultural competency training for mainstream medical professionals. Many Māori also called for a more holistic approach to health.

Better support information: A number of participants suggested that better information regarding social and financial support services was needed.

Consultations suited to those with multiple conditions: While generally the participants were satisfied with the service they received from their health providers, it was commonly suggested that appointment times be extended for people with multimorbidity to allow enough time to fully discuss their conditions. Furthermore, some suggested that health professionals could improve their practice by being seen to focus fully on their patient during the consultation and to attend to their needs as a 'whole person'.

Single point of care: Some participants discussed their desire to have one health professional responsible for all their care, to avoid complications from treatment for their different conditions.

Discussion

Multimorbidity has become 'the most common chronic condition'[5] and the major reason for healthcare expenditure in many countries.[5,24] This qualitative research identified patients' perspectives on living with multimorbidity, and is one of the first to focus on indigenous people. For many participants, multimorbidity disrupted their 'normal' life and created numerous new challenges that they had to learn to manage. Challenges included the activities of everyday life, managing work and, for some, leaving the house. Participants identified multiple coping strategies. As found in other research, the most important for many was a positive attitude.[25,26] Nearly all participants spoke of needing care and support from family and friends to manage their health, a key coping mechanism identified in the literature.[22,25,27,28] Managing multiple medications was a key concern for most, and remembering to take medication was a problem for which many participants identified coping strategies. Participants were also concerned about the side-effects and cost of taking multiple medications, which lead to some participants skipping or stopping their medication in an attempt to self-manage their conditions. These findings on medication concerns were a common theme in the literature.[12,22]

In common with other evidence,[29] participants spoke about the healthcare system. Travelling to appointments was often difficult, especially for those who did not drive and those who lived in rural areas, a finding in keeping with other international studies of chronic illness.[30] The implication for health service planning is clearly to focus on providing the most appropriate number of consultations for effective care, and not to burden patients with multimorbidity with frequent episodic single-illness appointments. Similarly, consultation length and context have been debated in relation to chronic and long-term illness, with a number of responses suggesting including longer consultations.[29,31] Health systems in many OECD countries have identified potential changes in consultation structure to try and accommodate the needs of patients with multimorbidity, though their success will be dependent on the degree to which their structure and function can accommodate change. In New Zealand, primary care consultations usually require a patient co-payment. In recognition of the burden placed on patients with multiple conditions, the government introduced 'Care Plus' where patients get longer consultations with both a GP and practice nurse, free of charge, to provide more coordinated and integrated care.[32] Important themes, including effective communication, longer consultation times and interpersonal continuity of care, are echoed in a recent BMJ editorial on better management of patients with multimorbidity.[29]

Internationally, successful management of multimorbidity demands a specific response to the cultural needs of increasingly diverse populations. In this study, indigenous Māori and migrant participants expressed the need for holistic and culturally competent health services. This could be achieved through an increased focus on cultural competence in healthcare training, including immersion at an early stage and an increased indigenous workforce. A significant increase in Māori medical graduates bodes well.[33] Participants had many recommendations to improve support for people living with multimorbidity. Suggestions for managing multiple medications are supported by a recent systematic review that suggests that fixed-dose combination pills and unit-of-use packaging are likely to improve adherence.[34] Patient-held medication records were recommended, with Whyte[35] finding that they are favoured by patients and effective in assisting recall. A similar study using pictures of medications alongside explanations of their purpose and dose had a significant effect on self-efficacy and adherence.[36] More recently, studies focus on smartphone applications;[37] however, while these applications had a positive effect on recall and enhanced adherence through reminder services, they are limited to those with the correct types of phone. Better care coordination and home-based care were suggested to avoid the challenges of travel.[38] There are calls for the development of new care coordination interventions for people with multimorbidity.[18,19,22,38,39] Calls for culturally specific services, cultural competence training for staff and a holistic approach to healthcare are other aspects equally supported in the literature.[40–43] Requests for better information about support services need to be addressed, possibly through accessible lay guides and user-friendly application processes. Despite reported high levels of satisfaction, some participants called for changes to healthcare processes, such as more patient-focused care, longer appointment times and having a single health professional for all specialist care, as reported elsewhere.[29,44,45]

The complexity of multimorbidity does not fit naturally within a healthcare system siloed by single diseases. Patients often described feeling overwhelmed by having numerous health services to access, alongside different health professionals and multiple medications. A recent Cochrane review[1] looked at multiple interventions targeted at improving the outcomes of patients with multimorbidity. Of the 18 studies examined, 12 focused on changing the actual organisation of care delivery, either through case management or enhanced multidisciplinary teamwork. The remaining six centred on patient-oriented interventions such as increasing confidence for self-management through various programmes and initiatives.

This research suggests that changes are needed to the way in which healthcare is organised and delivered in order to meet the complex needs of multimorbid patients.

Strengths and weaknesses

All phases of the investigation have been described, and the study followed criteria of quality in qualitative research. In preparing the manuscript, we followed the consolidated criteria for reporting qualitative research (COREQ).[46]

While caution is needed in generalising these findings to other nations, the New Zealand health system has much in common with health services in other OECD countries. Further, the study provides valuable perspectives on multimorbidity in indigenous people and those under 65, populations understudied in this arena. The study highlights the value of focusing on multimorbidity to capture the complexity of multiple, rather than single, conditions. It provides further evidence from a patient perspective about the challenges of this condition and reminds policymakers, funders and providers of the value of gaining patients' voices to identify solutions.

Further research

Future areas of research include triangulating the patients' perspectives with those of health professionals, funders and policy-makers, and undertaking intervention and cost-effectiveness research. The findings are currently being used to inform the development of a national survey, quantifying patients' perceptions of living with multimorbidity.

Conclusions

For many participants, living with multimorbidity disrupted their 'normal' lives, posing challenges in many areas that they needed to learn to manage. These included: coping with everyday activities such as eating and toileting, coping with work and managing multiple medications. Dealing with the health system also poses challenges, such as accessing appointments and having enough time to discuss key issues. Cultural competency, good communication, clear information and continuity of care were all valued. With this in mind, changes to the health system are needed to meet the complex needs of multimorbid patients. Participants in this study have many recommendations including: support to manage multiple medications, longer appointment times especially in primary care, culturally competent health services and one professional to coordinate all specialist care. Changing the siloed health system developed to address a single issue is essential if the challenge of multimorbidity is to be met. Urgent action is needed to reorganise the system in New Zealand and elsewhere so it is 'fit for purpose' to manage multiple conditions effectively and efficiently. This has the potential to dramatically improve the lives of the many people living with multimorbidity, reduce inequity for those living in socioeconomic deprivation and for Māori, enhance the experience of clinicians working with multimorbid patients, and reduce the significant costs to the health sector and wider society.

Table 2: Participants' quotes: living with multimorbidity.

Category	Code	Quote
What is it like?		"I was in denial for several years." (FG3) "You've got to be this close to death before you think 'oh shit, I'd better do something'." (INT1) "Oh we've managed very well. It's the bad look with the walking stick in one hand and a chainsaw in the other, but I still get work done." (FG2) "Sometimes I'm pretty good. Some other times I have trouble walking and puffing away." (FG1) "…it's taken a lot of the joy of life." (FG4)
Disrupting normal life		
	Eating	"So I might be at a marae [Māori community centre], and then I've got to leave whatever it is that I'm doing, to get something to eat." (INT11)
	Sleeping	"And in the early days I found it very difficult. Because I was told to take the medication in the morning, and I had a full-time job at that stage, and I used to fall asleep—I was a postie—and I used to fall asleep on my run, because the medication would knock me out so much." (FG3)
	Toileting	"I might be doing a jig and holding on to everything, and crossing my legs, running ... it's not uncommon for me to turn up at my mum and dad's house, and run in the door and head straight for the toilet. Screaming while I do it." (INT5)
	Mobility	"And I've been stuck all sorts of places. And I'm terrified, because it's not like I can ... because I've got walking sticks with me. You can't get outside in the blowing wind and walk with a walking stick." (INT12)
	Employment	"So it did really impact upon my work, to such an extent that I was off for considerable amounts of time. And I was making significant mistakes. So then I had to basically leave that work." (INT10)
	Leaving home	"And I went off my Furosemide for about three, four months, because I found them to be a nuisance when I go out. I can't go out, and you know, have to stay indoors." (FG1)
Coping strategies		
	Positive attitude	"It doesn't really worry me." (FG2)"My mantra is every day above ground is a great day." (FG4)
	Learning to manage	"I've learnt to manage things." (INT12) "Once I got to grips with what I had, and how I needed to look after it, everything settled down for me again, back to normal." (INT3) "I do try to manage as best as I can." (FG1) "You live with it." (FG3)
	Independence	"So I fight all I can to be independent." (INT12) "But the idea is I think to help yourself while you can. Once you start relying on people, then you find … you fall through that gap." (FG3)
Care & support		"I think there are a number of things. There's the old issue of WINZ [welfare services] not really explaining what's available to people … If you don't ask, then they won't tell. So there's still that. That's always been a problem." (INT9) "… you got to get this piece of paper and that piece of paper and that piece of paper and that piece of paper. Then by the time you go, you don't want ... you just go, 'stuff it'." (FG5)
Managing medications		
	Remembering medications	"Sometimes they're a problem [medications] and I have trouble remembering. But yeah, it's about trying to remember". (INT7) "What I would like to see is one pill for everything. No matter how big the pill is, one pill. Get it out the way." (INT9)
	Keeping to routine	"But I know pretty well, because I've been like this for fourteen years with the pain sort of thing, so I just know what to take. Sometimes I might be an hour out, but an hour's nothing. But no, I know all about that." (INT12)
	Cost of medicines	"I used to live on noodles, home brand noodles. And my son would say; 'where's the food mum?', and I'd say, 'we have to live on noodles, I need my medication'." (INT8) "I put my scripts in last week, but I could only afford to get two things out, which I really needed, but I always keep heaps anyway, just in case I can't afford to get them." (INT15)
	Self-management	"So I'm continuing that way, not taking it (a tablet) every day, but I take it every other day. Because I believe that it does help ... I don't feel any pain and that, so it must be working alright." (FG3)
	Knowing own body	"Those doctors have got to listen to us because we know that body." (FG4)
	Trial and error	"That's about it, really. Just yeah, the mix and match, and the sort of chemistry of trying to get the right drugs." (INT5)

FG= focus group
INT=interview

Table 3: Participants' quotes: the health system.

Category	Code	Quote
Travel to appointments		"The main issue is our transportation there. Because we are not eligible to claim anything, actually." (FG5) "I think that those of us in the urban sense are far luckier than our whānau in the country areas, because they don't have the services that we can access here." (FG6) "… if I wasn't driving, I'd be a dead duck. I really wouldn't be able to cope …. my driving—they're getting very, very tough …" (INT2)
Appointments		
	Having to wait for appointments	"The only thing I find coming here is that if you go and make an appointment, they keep ... oh not all the time, but they say oh, he can't see anybody till next week." (FG1)
	Wanting to see same health professional	I think there is a problem here … where we are today, we used to have doctors of our own. But going up to the doctor's today, you go up to a different doctor. There's three different doctors." (FG5)
	Length of appointments	"My wife had a couple of complaints and she said, 'oh, we're going to the doctor today. We'll talk to him about it.' And she started to talk to him; she said there's this and that. And he said, 'I'm sorry, you've only got fifteen minutes.' (FG4)
Cultural competence		"I tend to discuss only the wee points with my doctor, so we don't have a really good relationship. We're from two different cultures, and we don't like each other." (FG6) "They were Pākehā and I don't think … they were maybe culturally aware." (INT7)
Communication		
	Explaining everything	"And for me I was very fortunate, because the people that looked after my diabetes were very good, explaining everything, every step, what was happening and also the medication and all that, which I was quite pleased about that." (FG3)
	Discussing options with health professional	"No no, if I'm really happy I can say that to him (doctor). I know if I really don't want to go that way, and I think they suck, I can say that to him. So he is like a buffer." (INT5) "If I've got anything on my mind I've always got someone to talk to." (INT15)
	Feeling listened to	"You can tell he's not listening to you. You know, he's either on his machine or doing something." (FG1) "You'd see him looking at his computer and you wonder whether he's listening to you or not." (FG4)
	Understanding whole person	"What just keeps coming into my head is, seeing conditions or a person as a whole ... and I suppose they need to upskill, in terms of looking at a person and finding out where else they might be going for appointments or checkups or referrals." (INT5)
Integration of care		"Oh when I go to the GP, he goes 'oh you're seeing the asthma clinic next week. Tell them what's going on'. Or I see the asthma clinic, [they say] 'when are you seeing rheumatoid next?'" (INT4) "… how each doctor has a different opinion on how you should be treated." (FG6) "... everything is siloed, you feel like you're a jigsaw cut up into pieces. The disconnect is the biggest problem." (INT5)
	Receiving conflicting information	"And from that disconnect you're getting conflicting bits of information about the same parts of your body, or your condition or your disease, from their interpretation." (INT5) "... you've got the diabetes who are worried about the sugar, but they're not too concerned about the fat intake. And then you have the [other] dietitian who comes in totally different." (INT1)

FG= focus group
INT=interview

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