Qualitative Health Research

In pursuit of a person-centred approach to care delivery: A qualitative descriptive study of the patient experience of a long-term conditions clinic in general practice.

Journal:	*Qualitative Health Research*
Manuscript ID	QHR-2023-0758.R3
Manuscript Type:	Research Article
Keywords:	patient experience, multimorbidity, person-centred care, qualitative description, framework analysis, long-term conditions
Methods:	Qualitative Methods < Research Design, Interviews < Research Strategies
Regions, Cultures, and Peoples:	Britain < Western Europe < Europe, Europeans

Wilson G, Hutchison JS. In Pursuit of a Person-Centered Approach to Care Delivery: A Qualitative Descriptive Study of the Patient Experience of a Long-Term Conditions Clinic in General Practice. Qualitative Health Research.

DOI: https://doi.org/10.1177/10497323241272003

Table 1: Five stages of framework analysis undertaken.

Familiarisation	The researchers (GW and JH) independently listened to the audiotapes and read the interview transcripts and fieldnotes multiple times. They immersed themselves in the data, making note of key ideas, anything of potential significance, and any initial recurrent themes that emerged.
Identifying a thematic framework	GW and JH compared and agreed the emerging themes and sub-themes. This included some themes from the a priori issues and interview topic guide, but themes were also developed inductively from the data itself. These became the basis of the thematic framework which was formulated into a numerical system for convenience.
Indexing	Transcripts were revisited and sections of the data were identified that corresponded to a particular framework theme. Data were labelled with the relevant number from the thematic framework. GW and JH divided the transcripts between them to apply the thematic framework. Afterwards, they reviewed each other's labelling and any disagreements were resolved through discussion (Malterud, 2001).
Charting	Specific pieces of data identified through indexing were organised into thematic charts in a matrix format. Charts were ordered into rows and columns populated by participants (cases) and framework themes. The participant's responses were entered under the relevant heading – using either key words, paraphrases or snippets of data as an aide memoire.
Mapping and interpretation	The researchers attempted to develop and refine categories, looking for patterns and associations in the data. At this stage of the analysis, they assigned 136 categories. After examining for meaning, repetition, similarities and associations, the categories were narrowed down to a total of 49. This led to the final identification of four key themes. Through this systematic process the researchers were able to revisit the transcripts to check the supporting quotations truly reflected/supported the identified themes

Table 2: Collated Demographic Data

Gender	**Male** n=5	**Female** n=7	
Ethnicity	**White and English** n=11	**Not stated** n=1	
Number LTC	**Two LTCs** n=5	**Three LTCs** n=7	
Years living with LTCs	**4-10 yrs** n=3	**11-20 yrs** n=6	**21-40yrs** n=3
Employment status	**Self-employed** n=1	**Retired** n=10	**Unable to work** n=1

LTC included - type 2 diabetes, chronic obstructive pulmonary disease, stroke, hypertension, rheumatoid arthritis, ischemic heart disease, atrial fibrillation.

n = number of participants

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Abstract

Innovative ways of working are emerging in healthcare to meet the complex needs of people living with multiple long-term conditions. Whilst these initiatives are often measured for their health and economic outcomes, few studies prioritise the patient experience. This qualitative descriptive study is one of a few studies exploring the patient experience of attending a dedicated long-term conditions annual review clinic in a primary care setting in England. The service model aims to provide a person-centred, holistic approach to the management and support of people living with multiple long-term conditions. The study presents findings from in-depth interviews with 12 participants. Data analysed through framework analysis revealed four themes relating to the patient experience: the clinic as a place, continuity, staying healthy, and partnership opportunities.

Results highlight the challenges to providing personalised care. We found that attendance at the clinic prompted self-care behaviours, however, patients wanted a more holistic, integrated and consistent service that provided continuity of therapeutic relationships that involved them in decision-making and care planning. We conclude that the experience of patients in this study suggests this service model can enable patients to manage their health and improve wellbeing, however, whilst a person-centered philosophy may underpin service models, our research shows that ensuring this philosophy is born out in service delivery and recognised by patients, is problematic. Therefore, service providers need to recognise the values and perspectives of patients, aligning these with the design and delivery of services.

Keywords: Patient experience, multimorbidity, person-centered care, qualitative description, framework analysis, long-term conditions

Introduction

The care and management of people with long-term conditions (LTCs) is thought to be one of the greatest healthcare challenges of the 21st Century due to the adverse consequences experienced by the individual, their families, economies and health systems (Pearson-Stuttard et al., 2019; Whitty, 2017; World Health Organization (WHO), 2023). Developments in medical science have led to improved health outcomes through better understanding of diseases, earlier diagnosis, and the availability of sophisticated therapeutic options (Brown, 2015). These advances have benefited people with LTCs, enabling them to live longer lives with conditions that previously would have been fatal (Soley-Bori et al., 2021; Whitty, 2017). This combined with greater life expectancy contributes to the growing number of people living with LTCs (Kingston et al., 2019; Stafford et al., 2018).

In most developed countries, the rate of increase in healthy life expectancy has not kept pace with overall life expectancy (Jivraj. 2020). Whilst people are living longer lives, they are not always living healthier lives with some individuals experiencing moderate to poor health in their later years often caused by LTCs (Office for National Statistics, 2022) Living years in poorer health is not exclusive to the older population; an increasing number of young and middle aged adults spend years in poor health due to LTCs (Barnett et al., 2012; Frølich et al., 2019; Jivraj et al., 2020; Stagg et al., 2023; Welsh et al., 2021). The worsening health in people of multiple age ranges, poses challenges for healthcare service providers who are already dealing with the demands of a growing population living longer lives. This suggests that in the future, more individuals are likely to require health care services at younger ages and consequently rely on them for longer periods.

Many people live with more than one long term condition (also known as multimorbidity) and the numbers are steadily rising (Whitty, 2017). There are wide-ranging definitions of multimorbidity in the literature that vary in the type, number and severity of conditions included (Ho et al., 2022; Johston et al., 2019). For clarity, the definition of multimorbidity used in this paper is one proposed by the Academy of Medical Sciences (2018, p. 22-23): “the co-existence of two or more chronic conditions” which can be physical non-communicable diseases, mental health conditions or infectious diseases, all of which are of long duration. Added to the lack of consensus over a definition for multimorbidity, the term itself has come under criticism. The Russel Group of Charities identified that people living with LTCs feel the term multimorbidity is medically orientated, has negative connotations, and does not reflect the complexities of living with multiple conditions (Taskforce on Multiple Conditions, 2018). Therefore, in this article, the term multiple long-term conditions will be used instead of multimorbidity where possible.

Approximately 37% of adults globally live with multiple LTCs (Chowdhury, 2023). Prevalence increases with age and with socioeconomic deprivation, with people living in deprived areas developing multiple LTCs much earlier than their more affluent counterparts (Schiøtz et al., 2017; Violan, et al., 2014). Projections suggest that approximately 17% of the population in the United Kingdom (UK) aged 65 and over, will be living with ‘complex multimorbidity’ (four or more LTCs) by 2035, almost double the prevalence in 2015 (Kingston et al., 2018).

People living with multiple LTCs tend to use health care services more intensively than people with a single or no LTC, most notably in primary care settings where they take up more than half of all consultations (Cassell et al., 2018; Muth et al., 2014; NICE, 2016). The intensive use of health care resources by people with multiple LTCs extends across the wider health care system and includes higher use of unscheduled emergency care, more frequent hospital admissions and longer lengths of stay (Cassell et al., 2018; Skou et al., 2022; Stafford et al., 2018). Not only does this increase the cost burden on health care systems (Soley- Bori et al. 2021, Tran 2022), the direct and indirect costs of living with multiple LTCs can place a significant financial burden on the individual (Larkin et al., 2021; Skou, 2022).

People living with multiple LTCs are at greater risk of premature mortality, polypharmacy, functional difficulties, mental health problems, increased risk of disability, and can experience poorer quality of life than those without chronic illness (Hajat & Stein, 2018; Skou et al., 2022; Wallace et al,. 2015). Furthermore, the impact of living with multiple LTCs can result in a high treatment burden for those individuals (Rosbach & Andersen, 2017). For example, people living with multiple LTCs are often required to attend numerous appointments with different specialist teams for management of each discrete LTC where treatment is focused on single disease guidelines. This can result in poorly coordinated and fragmented care, that further complicates management strategies (Sinnott et al., 2013; Skou et al., 2022).

It is widely recognised that radical change in health care design is needed to better support people living with multiple LTCs (Nolte et al., 2014; Wagner, 1998; WHO, 2013). Thus, new models of care aim to move away from paternalistic approaches, that view patients as passive recipients of care, towards person-centred approaches that support people with multiple long-term conditions to play an active role in determining their care needs (Imison et al., 2017; NHS England, 2019). National guidelines on assessment and management of multimorbidity in England recommends that care is tailored to the individual needs of patients, their health priorities, and treatment preferences through formulation of a personalised care plan jointly developed between the clinician and the patient (National Institute for Health and Care Excellence (NICE), 2016).

Models of care have been developed that attempt to provide a person-centred focus by offering comprehensive and holistic approaches to multiple LTCs management, placing the person at the centre of their care (Muth et al. 2014; NICE 2016; Smith et al., 2021; Wagner, 1998). Haines and Kirk (2020) outlined the benefits that people experienced from an annual review and care planning service for those with cardiovascular disease and multiple LTCs. Their results suggested, because of attendance, patients understood their conditions better and felt more able to cope and engage in self-care. Other researchers have provided evaluations of primary care services for people with multiple LTCs using a one-stop-shop approach that provides access to a range of services in one place. Results suggested improved health outcomes, but other than the use of patient reported outcome measures (PROM) the patient experience was not considered (Bonner et al., 2020). Salisbury et al. (2018) undertook a large cluster-randomised controlled trial that incorporated patient-centred strategies in the management of multi-morbidity in primary care. Their 3D approach to care (incorporating dimensions of health, depression, and drugs) provided patients with multiple LTCs with comprehensive reviews rather than separate reviews for each LTC. They found mixed results with no improvement in health-related quality of life. Only 49% of participants received the two intended 3D reviews, impacting on the findings (Mann et al., 2019). Their participants, however, appeared to value the comprehensive reviews and reported increased perception of ‘patient-centred ‘care. We note the use of ‘patient-centred’ rather than ‘person-centred care’ described in this study.

Person-centred care (PCC) and patient-centred care are terms that are often used interchangeably in health care literature and in health care practice. Although the concepts share similar features, several commentators maintain that there is an important distinction between these two (Eklund, 2019; Harding et al., 2015; Zhao et al., 2016). It is beyond the scope of this article to consider the PCC versus patient-centred care debate in depth. For clarity, we use the term person-centred care throughout this article, as people with LTCs only spend a few hours per year as a patient accessing health care, spending the rest of the year managing their conditions in day-to-day life (Eaton, 2015).

Despite the development of new care models aimed at balancing the dominant disease-centric biomedical model with a more holistic person-centred approach for people with multiple long-term conditions (LTCs), quantitative measurements of health and economic outcomes often take priority over evidence based on patient experience when evaluating the success of a service. This highlights a gap in the literature regarding the subjective experiences and perspectives of individuals living with LTCs when encountering these care models.

Purpose of the study

This study provides valuable insights into the firsthand experiences of patients with multiple LTCs attending a dedicated annual review clinic. The clinic is designed to offer a more holistic and PCC approach for patients by addressing all their conditions in a single appointment. Gaining insight into the patient experience of such initiatives can assist in tailoring health care services to better address the needs of the increasing number of people living with multiple LTCs. This paper presents findings from a qualitative descriptive study that explored the experience of people with multiple LTCs who attend an annual review clinic in a GP (general practitioner) practice in a coastal town in the North-East of England. The practice is situated within an area recognised as one of the most deprived coastal neighbourhoods in England, and like many coastal communities, has some of the poorest health and wellbeing outcomes in the country (Whitty, 2021). Conducting health research in areas such as this contributes to valuable knowledge about access to services and standards of health care available in these underserved populations.

Method

Design

A qualitative descriptive design was chosen for this study. This approach is often used in nursing and health care research when exploring the patient experience of illness and/or health care related interventions, particularly when little is known about the topic of interest (Doyle et al., 2020; Kim et al., 2017). With its philosophical roots grounded within naturalistic inquiry (Lincoln & Guba, 1985), qualitative description positions itself within a relativist ontology which holds the view that no single reality exists. People construct their own reality based on their subjective experience (Bradshaw et al., 2017). Epistemologically, qualitative description is situated within subjectivism, a philosophical perspective that accepts that meaning is imposed on the object by the subjective consciousness, experiences, and perceptions of the individual (the subject) (Moon & Blackman, 2014). Within this framework, researchers acknowledge that knowledge is constructed through the unique perspectives, meanings, and interpretations of the participants involved in their study. Therefore, qualitative descriptive researchers need to remain near to the data during data analysis and provide rich descriptions close to the language used by participants to describe their perceptions and experiences of an event or intervention (Neergaard et al., 2009). By capturing the voice of participants with first-hand experience of the phenomenon, qualitative description can generate new insights that shape real-world clinical practice and influence service improvement (Chafe, 2017; Neergaard et al., 2009).

Setting and context

The design of the LTCs clinic involved in this study was based on the Diabetes year of care model (Diabetes UK et al., 2011) and on patient responses to a previous survey at the practice. The clinic was designed to offer a one-stop-shop approach to managing the care of people living with two or more of the following LTCs: hypertension, diabetes, ischaemic heart disease, stroke/transient ischaemic attack, heart failure, chronic obstructive pulmonary disease/asthma, and dementia. This approach was aimed at coordinating care to prevent unscheduled hospital attendance, avoid unnecessary polypharmacy, and reduce cost burden. The underpinning philosophy of the service is to provide a holistic, person-centred approach that considers the whole person rather than a set of single diseases. The service brought together GPs, nurses, pharmacists, and patients with the aim of increasing the knowledge, skills, and confidence of patients to self-manage their condition, and make shared decisions about their care needs, supported through collaborative personalised care and support planning.

The clinic model involved a two-stage process - a pre-visit review followed by a booked appointment with a nurse or GP a few weeks later. The first stage included; attendance for pre-screening tests, including blood and urine tests, prior to an appointment at the LTCs clinic; completion of a health and social care self-assessment questionnaire to identify issues most important to discuss at the forthcoming LTCs review appointment; a pharmacist records-based medication review to check for cost effectiveness and unnecessary prescribing; and a GP review of the medical notes to check and confirm diagnoses and make recommendations for treatment changes based on the findings of the pre-visit review. During the second stage of the process, recommendations were discussed with the patient at their LTCs clinic appointment, led by a Practice Nurse or GP. During this visit individuals received a comprehensive check of their multiple LTCs, screening for falls, frailty, depression and other conditions, relevant Quality and Outcomes Framework (QOF) reviews and were signposted or referred to specialist support where indicated. At the end of the appointment, patients were to be given a copy of test results and a personalised care plan developed in collaboration with the nurse or GP to aid self-management. Those at high risk from hospital admissions were also to be followed up with an appointment or telephone review.

Sampling and recruitment

Purposive sampling was used to recruit patients registered with the GP practice who attended the LTC clinic. Congruent with qualitative description, this sampling approach is beneficial when attempting to obtain broad insights and richness of information from participants who have the required experiences and qualities needed for the study (Kim et al., 2017). Potential participants were identified by the GP practice from their database of people who had attended the LTC clinic. The researchers did not have access to any of these peoples' medical records. Invitations to participate were sent by the practice to randomly selected patients meeting the following eligibility criteria: aged 18 or over; able to speak English and give consent; and who had attended the LTC clinic on at least one occasion, and at least three months from the date of the letter being sent to ensure potential participants were given enough time to judge the impact of their consultation.

Data collection

Consistent with a qualitative descriptive approach (Sandelowski, 2010), data were collected using one-to-one semi-structured interviews with patients who had attended the LTCs clinic. A semi-structured interview schedule was used that combined a set of predetermined open questions designed to elicit thoughts, feelings, and experiences of the participants and which gave the researchers the opportunity to explore responses in more detail. Written consent was obtained from participants prior to each interview, with interviews taking place in that person's home. Participants were allocated a unique study code to ensure anonymity.

Participants were interviewed either by GW or JH. To mitigate against the risk of the researchers generating diverse data due to differing interactions with the interviewees, the researchers agreed to follow an introductory script at the start of each interview and to make notes after each interview for comparison. The interviewers then listened to the first two interviews that each had conducted and compared field notes to ensure there was a consistent approach. In addition, a selection of transcripts from both interviewers were reviewed and consistency was agreed by an independent experienced qualitative researcher who was a Faculty member. Interviews lasted between 30 and 60 minutes and were digitally recorded to allow for verbatim transcription afterwards.

Data collection was considered complete when interviews no longer yielded new data of analytical significance (Guest et al., 2020). This occurred by the nineth interview. The researchers discussed findings from three further interviews after which they agreed saturation was reached. Data saturation is said to have occurred when no new insights are observed, and data sources repeat the same information rendering further data collection redundant (Saunders 2018; Hennink 2022). This study included a total of 12 interviews. Together with the principles of *data* saturation outlined above, the researchers independently determined that no new themes emerged from the three subsequent interviews. Considering empirical evidence suggesting themes can be identified at around 12 interviews (Guest et al, 2006; Francis et al., 2010; Namey et al., 2016; Hennink and Kaiser, 2022), the researchers felt satisfied that data collection were complete.

Data Analysis

Data analysis ran concurrently with data collection allowing for examination of the data as an iterative process, informing a reflective process that involved ongoing consideration of data collection methods; sorting and coding of data; and decisions made regarding data saturation. Data were analysed using framework analysis (Ritchie & Spencer, 1994) to ensure a transparent process that was systematic, sequential, and verifiable. This analytic method employs a five-step process: familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation. Each stage of data analysis was discussed between the two researchers. An advantage of framework analysis is its ability to enhance transparency and improve dependability through provision of an audit trail from which the interpreted themes can be traced back to the raw data (Ward et al., 2013). Framework analysis is also a useful approach when there are issues that have been identified as a priori that are salient to the aims of the study (Ritchie &Spencer, 2002). Thus, it was fitting to use framework analysis for our study as the funders of the research were keen to gain insight into the personalised care planning approach central to the LTC clinic design. The researchers, however, kept an open mind to ensure emergent data also guided the process, therefore allowing for both deductive and inductive analysis (Gale et al., 2013). Table 1 provides a step-by-step account of the framework analysis conducted in accordance with Richie and Spencer’s (1994) five stages.

Throughout the data analysis stage, both researchers were cognisant of their reflexive position taking into account factors that may influence data interpretation such as their life experiences and professional backgrounds (Berger, 2015). In addition to being academics, both researchers are also registered nurses with extensive experience of caring for people with LTCs. Through reflexive memo writing and discussions during data collection and analysis they were able to acknowledge individual and disciplinary biases, as academics and as registered nurses, that may have influenced interpretation of the data. GW came from a nursing background of chronic disease management, whereas JH worked with people with LTCs in an acute setting. Efforts were made to separate their experiences and assumptions to ensure best representation of the participants' perspectives. A reflexive approach contributes to the rigour of research by ensuring that analytic directions are defendable (Hunt, 2009; Thorne, 1997).

(Insert table 1 here)

Ethical considerations

Ethical approval was granted by The University of Hull, Faculty of Health and Social Care Research Ethics Committee, and Yorkshire and The Humber-Bradford Leeds Research Ethics Committee. Written and verbal information was provided to participants prior to agreeing to be interviewed. Participation was voluntary and people were free to withdraw from the study at any point without giving a reason. Identifiable information was removed before processing the data to ensure confidentiality and anonymity. It was acknowledged that some participants may find discussing their health difficult or uncomfortable and patients were asked to consider this before taking part. The researchers attempted to reduce the risk of any individual becoming distressed through close observation and careful, sensitive questioning. Both researchers have experience of qualitative interviewing and are also registered nurses with experience of talking to people in ill health. Prior to being interviewed participants were signposted to support, should they need it, from their GP practice, and where appropriate other means of support were suggested such as charitable organisations, for example, The Stroke Association or Diabetes UK.

Results

Five males and seven females were interviewed; they were mostly over 70 years old and retired (see table 2). Four themes were identified during the data analysis process: The Clinic as a Place, Continuity, Staying Healthy and Partnership Opportunities. Each theme is discussed below and supported by anonymised participant quotations to illustrate the generated data.

(Insert table 2 here)

Theme 1 – Clinic as a place

The first theme identified in the data considers the clinic as a place; a place where participants ascribed different meanings according to their experiences within the space. Three subthemes were identified that related to the clinic as a place: a place of reassurance, a place for the ill, a place that gives a prompt for action.

A place of reassurance

Most participants welcomed the clinic appointment as an opportunity to meet with a clinician to discuss their individual health needs. They valued the allotted time spent with a HCP (Health Care Professional). One participant described the encounter as extending the ‘arm of the doctor’ (P3) where, even if they saw the nurse or pharmacist, they could ask questions and express concerns about their health. Respondents reported a sense of reassurance that their health was being monitored on at least an annual basis, hoping that concerns would be picked up early and interventions put in place.

> P2: At least I know if I am getting the twelve months monitoring, I know everything is either going well or not…It gives me a confidence.
>
> P4: Well, I'd like to know, if anything is wrong, I would like to know about it.
>
> P14: It [the LTCs clinic] was only once a year and they thoroughly checked everything, so I was quite happy with that.

The convenient location of the clinic was also a source of reassurance and satisfaction. It avoided the need to travel to the nearest hospital for appointments with specialist services which was a 50-mile round trip for some patients. The GP practice where the research was conducted is in a remote coastal town in the north of England, poorly served by public transport. Being able to attend a one-stop-shop that viewed their conditions in the round, appeared to improve access to services for attendees.

> P9: Very handy because it's just a walk round the corner.
>
> P12: I said to the hospital I was coming here [the long-term conditions clinic] to this clinic here...It cost me £50 for a taxi to go [to the hospital].

A place for the ill

There were some comments from participants that demonstrated they were surprised by the letter of invite and there was some ambiguity around the purpose of the clinic and why they had been asked to attend.

> P11: I had a letter...It came as a bit of a surprise at the time, but I tend to be very good about anything to do with health…and never had no expectations at all. I just thought it was part of a system and join in.
>
> P3: the only thing is the wording [of the letter] on having your, on how they put it, to have your prescription, your blood's taken before you make the [LTCs clinic] appointment….it just doesn't make sense…Don't make your appointment before you've done this [arranged for pre-appointment screening], but the way they've put it, you know, what's it mean?

The ambiguity surrounding the purpose of the clinic may be linked to the way that people were invited to the clinic. Some commented that the clinic letter of invitation was unclear whereas others were confused about the sequence between attendance and investigations that need to be completed, resulting in questions about the purpose of clinic attendance.

Participants had varying perceptions about who should attend the clinic and the extent to which clinic attendance was appropriate for monitoring their LTC. One participant considered the referral to the clinic was due to a lack of management options – as if attendance was a last resort and that treatment options had been exhausted and nothing else could be done.

> P8: The doctor himself said he wanted me to go to the long-term clinic when they found out there was nothing else to do…Then I was told quite firmly, not rudely, quite firmly, go to the clinic. I did as I was told. Oh yes, nothing nasty. But just very firm. Please go to the [long-term conditions] clinic.

Other participants acknowledged that whilst they lived with chronic conditions, they did not consider that they warranted attendance at the LTC clinic as they had not experience chronic pain or disability.

> P8: I felt really that I didn't need to go [to the clinic] because I didn't feel as though I had a long-term illness…. I thought people who had pain, who had problems, you know, more fitted into that category than what I did.

> P3: it's [the LTC clinic] for people that's a lot worse than me, you know.

In contrast, and as highlighted in the quotation below, others felt their LTCs had a significant impact on their health and that clinic appointment times were too short – participants suggesting the time spent there was between 10 and 30 minutes. Some participants felt they needed closer surveillance and suggested appointments in the LTC clinic should be more frequent than once a year:

> P7: You're not long. Not very long at all [the appointment] but you see I suppose they don't have that time now…When you only do it once a year it's not like going on a regular basis.
>
> P11: I have insulin and tablets and...only meeting once a year to discuss that or be aware of that may not be good enough because there is a long time in 365 days.

Participants' perceptions of the purpose of the clinic ranged from feeling that their condition management at the clinic was because they were 'so ill' there were few treatment options left; to feeling that their illness was significant enough that they warranted longer appointment times; whilst others felt that they were not 'ill enough' to be offered an appointment at the clinic. This caused participants uncertainty about who should attend the clinic.

A place that gives a prompt for action

The prospect of an imminent appointment at the LTC clinic prompted some participants to take more notice of their conditions and to engage more proactively in healthy behaviours.

> P2: But yes, it helps me. It gives me the prod that I need sometimes just to get sorted you know?
>
> P3: Yes, because at least for three months before (the appointment at the clinic) I tried to be good. Or I have in the past, I didn't succeed last year. But, yes, it brings it aware, your self-awareness to the situation you are in. Where if you didn't go, it would be in the back of your mind, you know. I am not worrying about it, but you've got to think about it.

Clinic attendance had a positive influence on these participants' behaviour and contributed as a day-to-day reminder of their conditions. One participant (P3) commented that in the run-up to their appointment, they were more inclined to 'be good', in this way attendance acted as an external motivator that encouraged them to adopt and maintain a healthy lifestyle. This participant's comment demonstrates how perceptions about what is 'good' and what is 'bad' behaviour may exert an influence on health practices.

Theme 2 – Continuity

Participants' conversations drew attention to the '*journey*' they had taken to manage their LTCs as well as the '*journey*' they had travelled with others, like their GP or Practice nurse. One individual described the LTC appointments as an opportunity for their *'MOT time'* to ensure that they were road worthy for what lay ahead (P:14). The enduring nature involved in managing a long-term condition is evident in this participant's use of the phrase '*MOT time*' (The abbreviation that stands for Ministry of Transport, is an annual test of vehicle safety in the UK). The acronym is used as a metaphor by the participant to describe the benefits of regularly attending the clinic and the need for regular checkups to monitor his health over time.

These regular encounters with clinic staff provided continuity and contributed towards building relationships with their nurse, doctor or pharmacist at the LTCs clinic. The effectiveness of their condition management was perceived by participants to be influenced by the understandings established over time, providing assurance that clinicians knew their personal circumstances and medical history. Knowing staff and being known to staff made it easier for participants to connect and share personal information that could influence their care.

> P9: …Dr. [name] knew me from [surgery name] for 20 odd years.... Well, he used to know everything about me and about my husband …because my husband had a serious stroke 24 years ago, …and then he had a triple bypass.
>
> P2 Well I think it is important [to see the same person] because you get a rapport, you know? And it is a bit easier than meeting a stranger. And for me it is important
>
> P3: I would sooner see the same person so that they got to know you, I got to know that nurse, she knew me… it's going to see someone you know, rather than going to see a stranger which you aren't going to open up to

The importance of being 'visible' as well as being recognised as a person within a family context, rather than just a patient, was a recurrent message. These results show that the continuity provided by seeing the same staff member was important to participants.

Where multiple providers were involved in care, respondents were uncertain who had overall responsibility for individual elements of that care. Care delivery was perceived as fractured. Participants indicated concern that as a result, some health problems may be overlooked.

> P6: Well, I seem to go to little clinics for this little bit, that little bit, the other little bit. It's getting a whole picture that's the problem and you have to see a doctor for that. I think I haven't found any other way yet because nobody seems to be able to give you a whole picture.
>
> P18 The other one [clinic] I go every so often for a blood test for the rheumatoid arthritis. I can go here [to the LTC clinic]. The diabetes I can go here [the LTC clinic]. The arthritis I have nowhere to go and yes I am unhappy.

These results show that the provision of care for people with multiple LTCs in one clinic was valued. The importance of meeting with the same HCP during subsequent consultations to develop a rapport, was central to many of these participants discussions and appears important for establishing trust, and promoting assurance that their health was being monitored and well managed.

Theme 3- Staying Healthy

Staying healthy was another recurrent theme emerging from the data. Most of our participants were eager to either maintain or improve their health. Some participants were actively engaged in improving their health, whilst others were more passive. A few people felt fatalistic about their condition having a 'what will be, will be' attitude. There were some enablers and health management barriers, identified in participants' narratives. Knowledge, skills, and confidence were important influencing factors that contributed towards approaches to self-management, however, time pressures with work, access to transport and social isolation had a negative impact on participants' ability to develop wider support networks.

For example, talking about maintaining and improving their health, participants explained how clinic staff suggested less harmful alternatives to smoking and encouraged lifestyle changes to lower the risks associated with being sedentary.

> P4: I've started smoking one of these things now [e-cigarette] ......My own doctor tells me it's the best thing I ever did. I mean I'm 79 and I'd been smoking a long, long time…...I've been on one of them now nine months and I feel 100% better......And my long-term illness nurse says, "Your breathing is getting better."

> P3: I want to get healthier, but I don't know how much exercise I can do……..she said [Health Trainer] go to doctors and get a prescription to go to the gym and be monitored while you're doing the exercise, you will have somebody there with you all the time,

Some participants displayed confidence when discussing their health conditions and were positively seeking to manage their LTCs exploring ways to improve their health and wellbeing.

> P14: The blood and the pills and the checking is alright, but I don't think that's the final solution [for diabetes]. There's a solution, to exercise, eat properly and keep exercising. …I felt like even the doctors could say, 'Right, there's a prescription for a

> swimming class,' so that everybody that's overweight or that should have a free prescription can go to swim.
>
> P4: I know all about my [blood glucose] targets and stuff like that, what they should be first thing on a morning so, don't go to bed unless it's at least 8 or what have you.
>
> P3: I have a book here, I'm filling everything in……and this is my way of putting me first, it is doing that and counting my calories and my carbs and just seeing how I get on.

For some participants, attempts to modify their lifestyle seemed unrealistic and they spoke of their lack of desire to change. Just getting up each day was perceived as a bonus.

> P4: I don't look after myself all that much…. As long as I'm waking up on a morning, I'm alright, and as Bernard Manning once said, "if you're waking up on a morning and you don't feel wood on your elbows, you're alright.

Other people taking part in the study felt hindered by either not knowing what they could 'safely' do within the limitations of their condition or did not feel they were given the information they needed. Even participants who showed a willingness to engage in the management of their condition sometimes felt they were hampered in achieving this due to lack of skill and knowledge.

> P3: I want to get healthier, but I don't know how much exercise I can do.
>
> P7: they don't always explain what the purpose of the medication is for…it would be nice to know that, you know, what everything is for.
>
> P14: because they won't tell you what a good reading is [HbA1c]. What's the point in you telling me I'm 45, to me that means nothing.

The desire to be more informed was particularly evident when participants discussed test results or prescribed medication.

Some people welcomed the idea of using alternative sources for finding information such as the media or internet and were also interested in group self-management or peer support and sought signposting to additional resources, self-management support groups and other community-based services, from the HCPs at the LTC clinic. Others found it less appealing and found the prospect of talking in groups off-putting.

> P14: she [long-term conditions nurse] says, "Is there any way I can help you?" I says, "Yeah, I'd like to talk to people about it." She says, "Right, fair enough."
>
> P3: Well, it was like with the health trainers. Now, that is very good, they are sitting down with you for half an hour and giving you ideas and things that you should be doing or shouldn't be doing, should be eating or shouldn't be eating,
>
> P2: I do go online quite a bit, I'm on the diabetes website. Sometimes it is interesting, sometimes it is not. But yes, sometimes you find it contradicts itself. But I know I ask a question on there [online] So yeah, it's useful.
>
> P7: [I] declined to go actually, and you go to this diabetes thing, and you spend three hours or so, you know, in lectures and I thought well really, I don't really want to…. I didn't really fancy going into a room with people that I didn't know.
>
> P14: I thought I better do something and get some advice…You can go on the internet, but you don't get...a lot of the problems are not your problems.

Some participants felt that they would rather not receive health promotion information in a group setting, from people they did not know. Others felt the advice they could access on the internet may not be relevant to their situation.

Additionally, social isolation, work schedules and lack of access to transportation were barriers that prevented access to wider support networks. For participants who were limited by work or transport, the LTCs clinic was their only point of contact with HCPs to discuss health concerns.

> P2: There is a support group in [place name removed] that I am aware of, but I am not that interested in it, well at the moment anyway, because, as I say, I work, I am away a lot.
>
> P8: It's the only time I ever go anywhere is when she [friend] comes. She's got a car, she drives you see. She takes me where I want to go.

For most people interviewed the clinic appeared to be an important resource to acquire the knowledge, skills and confidence needed to promote healthy behaviours and was the preferred point of contact for health advice, however, for other people the clinic was just a starting point for them to explore the wider provision of healthy living advice and support available in the community. It was evident, however, that sometimes participants felt that the information they received during clinic attendance could have been more detailed and individualised for them.

Theme 4 – Partnership opportunities

When asked about the level of involvement in making care decisions, participant experiences varied. Some people suggested there was a collaborative approach taken in decision-making about their care, with practitioners at the LTC clinic, whereas other participants felt the clinician should take responsibility for decision-making, based on relevant tests and investigations. Other participants suggested that they may not have been involved or that they did not know they could be involved in decisions about their care.

> P3: They had suggested that I increase my [diabetic] tablets and I didn't want to…I said I haven't been very good [with diet] during the summer, so can we have the tests again in another three months…and it [HbA1c] had come down a bit, so the tablets weren't increased.
> P6: They [clinicians] make the decisions and I would tend to stick to their decisions.
>
> P14: Yeah, well I'd say the blood test does that [determines treatment decisions], doesn't it? It tells you what it is, and the nurse recommends it, and I will take their advice.
>
> P9: I didn't know that you could be more involved (in care).

A lack of effective communication and shared decision-making had a negative impact on medication adherence for one person we interviewed.

> P4: They give me one of these [inhaler]. The one I had was brilliant and they changed it. I said to chemist, "What's that?" He said, "It's a new inhaler." I say, "How do I use that?" …. So, any road, I don't use it [inhaler].

This participant said he stopped using his inhaler after it was changed without any discussion with him.

Although most participants did not recall having a copy of the care plan or did not seem to know what care planning was, several described discussions that suggested a care planning conversation had taken place, mentioning treatment goals, targets and receiving health promotion literature.

> P11: I am not aware of being set any goals except that I know that I should get this HSBC [HbA1c] figure down.
>
> P2: You sometimes get a leaflet or something, but there is no care plan as such.
>
> P12: You walk out (of the clinic) with a bit of paper and think 'what is that for?' It doesn't say anything really.

Those who did not recall having care planning conversations felt such discussions would help with the day-to-day management of their LTCs. Some participants commented that they would like their care to be more personalised and less routinised and felt that their individual concerns were not always a priority for the practitioner they spoke to.

> P 2 Because [with a care plan] you would then have, 'what is the word?' not a formula, you would have something that you could work against, formalise what you do every day.
>
> P 6 it would be nice as you get older to think I want ... they know about me. And they probably don't, they probably don't know very much about me at all
>
> P11: it seems to me that whoever interviews me and presents the results is more interested in the task than interested in me as a person…they look at the screen and they say "you are a 4.2 this…a 6.3 that, and an 8.9 this", so I am really just a set of numbers rather than somebody who has got a long-term condition.'

A few people in this study felt they did have some choice in the decisions made about their care, others felt there was little opportunity for choice and sharing decision-making, however, the majority felt they would like to be more involved in this process and wanted to be informed of the options available to them.

Discussion

Participants valued the LTC clinic, and their responses suggested that the benefits of attending included a feeling of reassurance, a prompt to engage in healthy lifestyle, and a cue for action towards positive behaviour change. How long these effects were sustained, however, is difficult to determine from our study. Although attendance was valued, at times there was confusion over the purpose of the clinic and who should do what. Candidacy for the LTC clinic appeared irrelevant for some participants who did not consider themselves to be ‘ill enough’ to attend. The perception of living with a chronic illness but not considering oneself as ill has been observed elsewhere in the literature (Brooks et al., 2015). Despite many participants identifying positive experiences when attending the clinic, results also identified areas for improvement, that involved clarifying the intentions of providing such a service and its key initiative - to provide shared decision-making and a person-centred approach to care delivery. Actions such as clarifying content and raising the personal salience of the invitation letter could help to reduce ambiguity (Sallis et al., 2016).

Participants wanted continuity in their care and would have rather seen the same person on each visit. This LTC clinic provided the opportunity for patients to engage in discussions about their health and wellbeing with HCPs. The value of time spent interacting with HCPs is reported elsewhere (Baker et al., 2015; Perry et al., 2016; Salisbury et al., 2019). Similarly, the importance of developing relationships to ensure continuity, is also a finding highlighted in other literature (Freeman & Hughes, 2010; Parker et al., 2010). The

WHO (2015) definition of continuity of care involves "the degree to which a series of discrete health care events is experienced by people as coherent and interconnected over time, and consistent with their health needs and preferences*"* (p. 47). Continuity is known to have positive outcomes for patient experience and adherence to treatment (Baker & Jeffers, 2016; Chen et al., 2017). In this study, relationships were central to participants' perceptions of continuity. When attending several clinics for single disease specialty treatment, our participants indicated dissatisfaction and confusion about who had overall responsibility for their care. Patients clearly valued the relationships, as well as the security and stability that LTC clinic visits provided.

Participants in this study were keen to manage their health and share in decision-making, although opportunities for this were not always obvious. Many were motivated to stay healthy and self-manage their condition, reflecting discourses drawn from broader political movements that encourage patients to make positive lifestyle choices and take responsibility for their own health (Ravn et al., 2016). Whilst some participants favoured directed care, others favoured explicit processes of shared decision-making where goals and plans of care were negotiated. This aligns with NICE (2009, 2016, 2021) guidelines that places emphasis on involving patients in care decisions to improve treatment adherence. Those participants that wanted to be involved in making decisions about their care, welcomed a collaborative approach to planning care, but many of those did not feel involved in recognised care planning activities.

Person-centred care is widely advocated in health policy, research and practice at national and international levels (WHO, 2015; NHS England, 2019), but its application can raise practical challenges. Our findings highlight how services aimed at providing person-centred care, may not always be experienced as such by service users, even though these philosophies may underpin the service design. Without interviewing staff working in the clinic, it is not possible to determine exactly what contributed to this outcome; however, comments from our participants correspond with findings from previous research.

Studies aimed at improving outcomes for people with multiple LTCs, have similarly noted difficulties in establishing effective person-centred care delivery (van der Heide et al. 2019; Peters et al., 2020) and are highlighted by participant comments in this study. Reasons that have been suggested for this include the heterogenic nature of the person-centred interventions used in these studies, lack of fidelity to those interventions by clinicians involved, limited staff training, difficulties adapting to new ways of working that were perceived as more time-consuming by clinicians, variation in roles and competencies of clinicians, and participants having to consult with a different clinician to the one they usually saw, affecting the continuity of care (Smith et al., 2021; Fortin et al., 2022). Other studies have demonstrated that services that take a task-orientated, population health-based approach, in preference to offering care tailored to the needs of the individual, are at risk of depersonalising care (Reeve et al., 2012). Personalising care requires a focus on what matters to patients. Recognising patients' priorities rather than focusing on disease and biomedical measurements, can improve their sense of well-being and relationships with HCPs (Chana & Ahluwalia, 2014).

Person-centred care is a diverse and multidimensional concept which lacks a consistent definition and agreement of methods of measurements (Mitchell et al., 2022). This may account for the challenges to implementing PCC. The result of this study suggests a tension between a service designed to meet policy aims and targets to reducing hospital admissions and providing a person-centred approach suggesting a gap between policy and practice (Reeves et al., 2014; Burt et al., 2014).

Some commentators have considered the tensions between providing evidenced - based health care (EBHC) and providing PCC (Kerry et al., 2020; Tonelli, 2020), suggesting that whilst EBHC strives towards looking for causality and generalised patterns from which to base interventions, the intentions of PCC models are diametrically opposed, focusing on the uniqueness of the individual. Wieten (2020) suggests that the privileging of EBHC leans towards providing services that are reductionist and depersonalising. The dissonance between the objectives behind the design of this LTCs service model and our participants' perceptions of that care, highlight the complexities of providing person-centred care (PCC).

Patient-centred care, patient partnership and engagement are stock phrases rooted in this LTCs clinic’s philosophy. Designing services from the “third person perspective” of the HCP, rather than from the “first person perspective” of the individual experiencing the service (Owens & Cribb, 2012, p.269), risks an “information asymmetry” between what is considered important to health providers and what matters to health care users (Barile at al., 2014, p. 211). It is becoming increasingly recognised that rather than viewing PCC as something that is provided to patients by clinicians, a shift in thinking is needed that embraces a partnership approach; builds on mutual respect, acknowledging the personhood of both the patient and clinician. This requires a transformation in the balance of power between patients and practitioners through epistemic reciprocity and the co-production of services (Loughlin et al., 2019; Dell’Olio et al., 2023). Co-production of health services may provide the solution to the dissonance identified in these participants' comments- that staff were more interested in tasks and numbers than in them as a person. Co-production approaches challenge traditional assumptions of health care as a provider-led service.

Co-production of health care services has been defined as "The interdependent work of users and professionals to design, create, develop, deliver, assess and improve the relationships and actions that contribute to the health of individuals and populations" (Batalden, 2018, p.2*)*. Designing services and values that are co-produced by both HCP and patients is not without its challenges. These include shortages of resource, the pervasiveness of an illness-centred approach to delivering care, perceptions of cultural distance and differences in understandings of health-related problems (Roberts et al, 2014). Co-production, however, is considered to enhance service quality, increase the effectiveness of treatment and sharing of ideas, improving patient satisfaction (Palumbo, 2016). This may be one solution to addressing the disconnect, identified in this study, between how a health service is delivered and how it is perceived by those who use the service.

Strengths and limitations

The strength of this qualitative research is in providing real-world insight into patients' unique experiences of attending a dedicated LTC clinic in primary care. We were not able to capture the impact of the clinic from the clinicians' viewpoint, to consider the perceptions and experiences of the clinicians themselves, however, the purpose of this study was to champion the patient's experience. These results need to be interpreted with caution as the study involved a homogeneous white, older population, and was conducted in one site in a remote coastal town, however, it aids the understanding of the needs and experiences of people living with multiple LTCs, offering useful insights into the challenges of care provision for this group of patients.

Conclusion

Patient experience is increasingly recognised as an important measure of the quality of health care provision in the National Health Service in the UK. Our findings indicate that a dedicated LTCs review clinic has potential to empower patients to manage their health and enhance well-being, however, this study identifies the difficulty in delivering person-centred care. We suggest there is a need to conceptualise what person-centred care looks like to patients at the outset of any new service. The dissonance observed between participants' perceptions of the service and the aims of the service model, demonstrate a need for cultural change and ways of working that are cognisant of the perceptual gap between HCPs and recipients of care. Designing services that are coproduced by both HCPs and patients, may be one solution to designing out any disconnect between how health services are delivered and how they are perceived. This requires a paradigm shift away from traditional biomedical models of care that prevail in current health service delivery, towards approaches focused on the individual's experiences of living with multiple LTCs and personal need.

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