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Title: Understanding Care Navigation by Older Adults with Multimorbidity: A Mixed–Methods Study Using Social Network Analysis and Framework Analysis

Authors:
Dr Jolien Vos (corresponding author)
University College London
University of Lincoln
School of Health and Social Care
Brayford Pool
Lincoln
LN6 7TS
j.vos@ucl.ac.uk

Dr Kathrin Gerling
Katholieke Universiteit Leuven

Dr Conor Linehan
University College Cork

Prof A. Niroshan Siriwardena
University of Lincoln

Dr Karen Windle
NatCen
Understanding Care Navigation by Older Adults with Multimorbidity: A Mixed–Methods Study Using Social Network Analysis and Framework Analysis

AUTHORS
Vos, J., Gerling, K., Linehan, C., Siriwardena, A.N., & Windle, K.
ABSTRACT

Background: Health and social care systems were designed to be used primarily by people with single and acute diseases. However, a growing number of older adults are diagnosed with multiple long-term health conditions (LTCs). The process of navigating the intricacies of health and social care systems in order to receive appropriate care presents significant challenges for older people living with multiple LTCs, which in turn can negatively influence their well-being and quality of life.

Objective: The long-term goal of this work is to design technology to assist people with LTCs in navigating health and social care systems. In order to do so, we must first understand how older people living with LTCs currently engage with and navigate their care networks. There is no published research that describes and analyses the structure of formal and informal care networks of older adults with multiple LTCs, the frequency of interactions with each type of care service, and the problems that typically arise in these interactions.

Methods: A mixed-methods study was carried out. Sixty-two participants, all aged 55 years or over, living in England, with two or more LTCs, were recruited and completed a social network analysis (SNA) questionnaire. Semi-structured interviews were conducted with roughly a 10% subsample of the questionnaire sample; four women and three men. On average, interviewees were aged 70 years old and had four LTCs.

Results: Personal care networks (PCNs) were complex and adapted to each individual. The task of building, and subsequently navigating, one’s PCN rested mainly on patients’ shoulders. It was frequently the patients’ task to bridge and connect the different parts of the system. The major factor leading to a satisfying navigation experience was found to be patients’ assertive, determined and proactive approaches. Smooth communication and interaction between different parts of the care system were found to lead to more satisfying navigation experiences.

Conclusions: Technology to support care navigation for older adults with multiple LTCs needs to support patients in managing complex health and social care systems by effectively integrating management of multiple conditions and facilitating communication between multiple stakeholders, while also offering flexibility to adapt to individual situations. Since quality of care seems to be dependent on determination and ability of patient, this leads to uneven care. Those with less determination, and less organization skills experience worse care. Technology must aim to fulfil these coordination functions, to ensure care is equitable across those who need it, not just those who ask loudest.

Keywords: Older adults; care navigation; multimorbidity; long-term conditions; social network analysis.

INTRODUCTION

Background

While people now live longer than previous generations, they do not necessarily live well for longer [Error: Reference source not found]. With the increase in life expectancy, there is also an increase in long-term health conditions (LTCs), such as arthritis, diabetes, and heart disease. In addition, a growing number of older adults are diagnosed with two or more LTCs, also referred to as multimorbidity [2-3]. Health and social care systems were primarily designed for people with single diseases and acute conditions rather than for the management of multiple LTCs, resulting in difficulties in care provision and navigation (i.e. finding the right type of care, in the right place and at the right time) for those with multimorbidity [4]. Care systems are, for example, often not connected in the way patients expect [5-6]. This can lead to expectations remaining unmet as well as over-, under-, and in-appropriate use of the care system [5,7-8]. Furthermore, the incurable nature of LTCs, combined with the burden they can place on people’s lives, increases the importance of maintaining and improving quality of life [4]. Patients with multimorbidity especially value clear communication, and accessibility of providers. Particularly for older individuals with multimorbidity, there is an urgent need for support in appropriately navigating the care system to maximise health and well-being.

Prior Work

One approach to addressing this need, is the provision of designated ‘care navigators’ - professionals who support patients in their ‘pathway’ or ‘journey’ through the care system. In their task of guiding patients through the system, care navigators focus on the needs of the individual. Studies in the cancer care setting have shown the benefits of care navigators [9-11]. However, despite having a positive effect on patient satisfaction, quality of life and functionality [7,12], the high cost of care navigators remains a barrier to their wider employment [Error: Reference source not found]. Furthermore, their involvement in the patient’s journey tends to be limited to short amounts of time [14] and to focus on single LTCs (e.g. cancer) instead of multiple LTCs [6].

A potentially more cost-effective, accessible and equitable solution lies in the use of technology to aid care navigation [8,15]. Indeed, it could be argued that care navigation is an information management and communication problem; these are exactly the types of problems that ICT is well suited to solving. Some work is beginning to emerge on this topic. For example, Yao et
al., [15] proposed the design of a navigation support system for patients modelled on decision-support tools more commonly designed for clinicians. By providing patients with a unified and integrated view of their specific care continuum, Yao et al. [15] aimed to help patient understand and manage their healthcare. Their prototype design did not directly involve patient data or consultancy, but focused on pathways derived from medical guidelines. Yao et al. [15] comment that navigation programmes need to truly focus on patients in order to help them to manage this task, suggesting that a better understanding of patients’ needs regarding care navigation and multimorbidity is required to design effective support systems. Zulman et al. [14] address this issue by outlining patients’ need. Three themes emerged from their study: “(1) patients with multimorbidity manage a high volume of information, visits and self-care tasks, (2) they need to coordinate, synthesise and reconcile information from multiple providers and about different conditions and (3) their unique position at the hub of multiple health issues requires self-advocacy and expertise”[14].

Zulman et al. [14] did however not provide a detailed understanding of stakeholders involved in the care network. No previous studies have investigated the structure of the care network of older people with multiple LTCs. There is very limited knowledge available to researchers on how older people with multimorbidity interact and engage with their care network. These gaps in knowledge make it difficult for anyone to design appropriate care navigation support for these patients.

Goal of this study
In order for technology to support older adults in care navigation, an understanding of both the care system, and people’s experiences of that system, is needed. This study is the first step in the experience-centred design [16] of tools to support care navigation. The goal of the current paper is to describe and analyse the challenges inherent to care navigation, and in doing so, to outline design opportunities for technology to support older adults with multimorbidity when navigating the care system. As such, we contribute to the current knowledge by providing a systematic exploration of older people’s existing experiences, needs and goals in care navigation, while relating these to their personal care network (the people providing them with care). Using a mixed-methods approach, this study aimed to identify the type and number of carers (formal and informal) involved in the care of older people with multimorbidity. Through quantitative (social network analysis [SNA]) and qualitative (framework analysis) methods we examined and explored older people’s experiences and needs in relation to navigating their care. Our analysis takes into account the breadth and depth of participant experiences, but still allows actionable reflections on challenges and opportunities for the human-computer interaction (HCI) community when designing for multiple conditions.

METHODS

Study design
A pragmatic mixed methods study was carried out in order to understand care navigation from the perspective of older adults with multiple LTCs (see [10,17] for detailed discussion of mixed method study designs). The intention was twofold:

1. Understanding Personal Care Networks (PCNs) surrounding older people with multimorbidity.  
   This included identifying which carers were involved, why and how were they involved.

2. Understanding the experiences of older people with multimorbidity in relation to care navigation.  
   This encompassed examining how the PCN currently functioned and how it should be functioning for older people with multimorbidity

Quantitative (questionnaire) data were needed to help answer the question of ‘who’ was involved in the PCN of a wide range of participants, and to some extent ‘why’ they were involved. Qualitative (semi-structured interview) data were used to give in-depth information on the latter, as well as details of ‘how’ those people were involved, and in ‘what’ way the network functioned. A tranche of quantitative data was initially collected and analysed. This initial analysis was used to guide the design of the qualitative interviews. Specifically, interviews focused on topics that were recognised as important in the initial analysis. Interviews were then started, with the remainder of the quantitative data being collected and analysed concurrently with the interview strand. Ethical approval for the research was obtained through the <removed for blind review> ethics board, and the <approving body> of the <national healthcare body>.

Sample and recruitment
Eligible participants had to be aged 55 years or over, living in England, and diagnosed with at least two LTCs. We aimed for a minimum of 50 questionnaire respondents and a 10% subsample for the interviews. The study was advertised via a number of methods. Firstly, emails and social media messages were posted by both a University and an age-related non-governmental organisation (NGO). Secondly, flyers were created and placed, with agreement, in churches, community halls and charity shops. Thirdly, posters and information sheets were placed in 101 general practices. Fourthly, people engaging with a pilot care navigation project run by an NGO were contacted directly. Once the questionnaire was completed, eligible respondents (i.e. those living locally to the lead researcher) were offered the option to participate further through a semi-structured
interview. Those who decided to do so, were contacted to further discuss the study, check their consent, and clarify any further questions. In agreement with the participant, a place for the interview was decided (usually the participant’s home).

Data collection
In order to understand the range of experiences encountered by people with multimorbidity in navigating the health and social care system, it was necessary to capture information about participants’ communications, interactions and relationships with a range of different people, services and institutions involved in their care. Two distinct instruments were designed to collect the data in this mixed methods study.

Social network questionnaire
Social network questionnaires have been found to be useful for the assessment of connections and relationships between people or social actors [18]. ‘Egocentric’ Social Network Analysis (SNA) is a sub-type of SNA that aims specifically to understand the relationships surrounding one focal unit or actor in a network [18]. Egocentric SNA provided a method for us to assess the patient’s perspective of their own care network. Very few examples of validated and non-validated questionnaires for social network data were found at the start of this study (e.g. [19-20]). Therefore, a new questionnaire was developed. Our questionnaire was designed primarily on ‘name generator’ questions. These questions asked participants which formal and informal carers they were in contact with, the frequency of contact and the reason for contact (e.g. treatment, support) (see Figure 1). The majority of questions were close-ended, allowing direct comparison of the data across participants (see Figure 1).

![Figure 1. Example question of social network questionnaire for the study](image)

An initial draft of the questionnaire was reviewed by six members of a Patient and Public Involvement group. Based on their feedback, an adjusted version was sent out for pilot testing among three members of the public (who met the inclusion criteria for the study), two members of a “Later Life” forum, and two academics independent from and unfamiliar with the
research. This group of people completed the questionnaire and provided feedback that led to final adjustments of the questionnaire (see Multimedia Appendix 1 questionnaire).

**Semi-structured interviews**
The questionnaire was not intended to provide nuanced data on, for example, the ‘strength’ of connections that patients had with care providers. In order to address this, semi-structured interviews were planned (see Multimedia Appendix 2 interview schedule). The final topic guide included questions on patients’ needs regarding (digital) care navigation support, and their current experiences and barriers to using such technology.

**Data analysis**
The study gathered both quantitative and qualitative data, thus requiring a number of different types of analyses, plus a strategy for integrating data across those methods.

**Quantitative analysis – SNA and descriptive analysis**
The current study used SNA to interpret questionnaire responses. In care settings, SNA has for example been used to describe and understand the social aspects of communication patterns [21], to investigate the impact of social capital on health and well-being [22] and to look at the influence of social networks on frail older people’s life satisfaction [Error: Reference source not found]. SNA include two main components: ‘actors’ and ‘relationships’. Actors in SNA are represented by points and referred to as nodes. Nodes are the individual units that are connected by the relations (ties). The ties (relationships) or ‘edges’ in SNA are represented by lines (see Figure 2) and can display any possible connection between the nodes of interest, such as friendships, collaborations, and information flows.

In order to visually support the analyses of these structures, SNA uses graphs also called sociograms [24], an example of which is shown in the simplified example in Figure 2. We used SPSS Statistics V22 (IBM Corp) for **descriptive analysis** of the data and Gephi 0.9.1 [25] as **visualisation and exploration** software assisting SNA and providing sociograms of the PCNs.

![Figure 2. Example network graph displaying nodes and edges](image)

**Qualitative analysis – Framework analysis**
Framework Analysis [26] was selected as the most suitable method to analyse the semi-structured interviews. Framework analysis is a specific type of thematic analysis, usually with greater emphasis on the transparency of the analytical process [26] and linkage between the stages of analysis [27]. Framework analysis was an inductive, iterative and continuous process. It allowed for concepts to emerge as we progressed through the analysis process. However, at the same time, we had a clear understanding of the purpose of the research and the question that needed answering [28].

The qualitative analysis involved three separate stages, although these were not necessarily linear in progression and moving between different stages was not uncommon. In the first instance, the transcripts were line-by-line coded. This process was assisted by the NVivo 10 software package, and resulted in several open codes (e.g. difficulties finding the ‘right’ person to contact, perception of limited communication between providers) that were later grouped together as categories (e.g. barriers in care navigation) and supported the themes from the framework. Secondly, both within and between transcripts, a search was conducted for remarkable and noticeable differences and similarities between participants (e.g. patients with family living nearby versus those with family further away). Thirdly, reoccurring codes, differences and similarities were grouped and brought together as subcategories within seven themes: (1) meaning of the personal care network (PCN), (2) structure of the PCN, (3) roles and responsibilities in the PCN, (4) first point of contact, (5) service organisation/operation, (6) PCN interaction and communication and (7) technology.
RESULTS

Sample characteristics
Sixty-two participants, all aged 55 years or over, living in England, and diagnosed with two or more LTCs, were recruited. Thirty-seven participants accessed the questionnaire via an online link, while 25 completed a paper version. Twenty-eight participants reported as male, 14 reported as female and the remaining 20 preferred not to say or left the question blank. On average, questionnaire participants were 72 years old (range 55-94 years). Participants indicated they had been diagnosed with a variety of LTCs, the five most common being musculoskeletal conditions, cardiovascular disease, bowel diseases, respiratory conditions and diabetes. Participants with conditions affecting cognitive and memory abilities were excluded from the study. No significant relationship was found between age and the number of LTCs (r=-0.112, p=0.505) and no significant difference was seen in the sample for the number of LTCs between men and women (F=2.327, t=-1.239, df=24 and p=0.227). All participants reported they had been diagnosed with their first LTC more than two years ago. The majority of participants that answered the question relating to the time of diagnosis (n=37) had their first diagnosis 10 or more years ago (51.4%, n=19/37) and 45.9% (n=17/37) had the diagnosis less than 10 years ago.

Semi-structured interviews were conducted with a rough 10% subsample of the questionnaire sample; four women and three men. On average, interviewees were aged 70 years old (ranging from 57-83 years) and had four LTCs (ranging from two to eight).

Understanding the PCN: Carers
To understand our participants’ personal care networks, we identified, for each participant, which carers were involved, as well as their reason for involvement. Across the questionnaires a total of 39 different actors were reported by participants (see Figure 3). Actors closer to the patient and conveying stronger ties (i.e. thicker lines), were more frequently indicated by participants. Consequently, actors further away from and connected with the patient through thinner ties were overall less indicated by the sample. The closeness or distance of these actors to the patient is also represented by the size of the nodes. Bigger and smaller nodes respectively reflect actors more or less frequently mentioned to be involved in the PCN of participants. On an individual level, the number of important actors varied across participants, from as little as one to as many as 20. Regarding participants’ contact with actors, similar results were seen. On average, the PCN of patients contained seven actors.

Figure 3. Actors involved in participants' personal care networks. Colours represent separate domains of care (Blue = HCC, Cyan = HCH, Purple = SOCC, Grey = IC).

Those (n=2/7) who lived further away from their immediate family and/or did not have certain people within that group (e.g. partner), tended to elaborate in greater detail the structure of those living around them. Interviewees who did not have their family nearby showed higher reliance on neighbours, friends and even people in the wider community.

Understanding the PCN: Domains of care
Four domains of care; health care actors in the community (HCC), health care actors at the hospital (HCH), social care actors in the community (SOCC) and informal care (IC) actors, were identified. Figure 3 displays the structure of the PCN according to these domains of care. The different domains of care were allocated different colours to provide a domain sensitive graph. The average amount of actors indicated as important per domain was slightly higher for HCC (four) than the
other domains (SOCC=one, HCH=three and IC=two). The domain specific averages relating to contact did not show much internal variation; generally, participants indicated three HCC, HCH and IC actors they were in contact with and one in the domain of SOCC.

Both the interview and questionnaire data suggested a smaller involvement of formal social care than any other type of care (i.e. hospital, primary care, informal and third sector care). Less than a third (30.6%, n=19/62) of the participants indicated one or more SOCC actors to be involved in their PCN. Over double this amount (67.7%, n=42/62) was reported for HCC actors and 51.3% (n=32/62) indicated the involvement of HCH and IC actors.

Understanding the PCN: Levels of care

Unlike the questionnaire, the interviews did not predefine domains (i.e., SOCC, HCC, HCH and IC) for inquiry. As such, the groups of care that emerged from the interview data were based on patients’ perceptions of the type or levels of support they provided. In other words, this added detail on why certain actors were involved in the patient’s care. When describing the PCN during the interviews, participants tended to distinguish three levels of support: support provided on a day-to-day basis, frequently used services/providers for monitoring and follow-up, and 'exceptional’ care delivered by professionals.

“there are local charities, there’s the stoma nurses, there’s the local Ileostomy association. I go to see a consultant once a year at the hospital so to me that is the…my care network, as well as friends and family.” (pp7)

The interviews revealed that daily continuous support was mainly provided by informal carers, whereas follow-up activities and expert care were situated respectively on the level of primary and secondary care.

“[…] So you’ve a group of more exceptional people to access than you have informal care givers who are there on a day to day basis. And then you’ve those that you basically access on a frequent basis to keep in check with the conditions that you have.” (pp5)

Integration of the data further led to the identification of five main categories of actors in the PCN (Figure 4): the patient him/herself (a), the GP practice (b), the informal network (c), the experts involved depending on the type of LTCs patients were diagnosed with (d) and additional services used as required (e). The first three (a-c) were found to be the ‘core’ of the PCN, remaining relatively stable across patients’ time living with LTCs. The presence and number of experts (d) and additional services (e) however were more subject to change.

Figure 4. Representation of the five separate care actors identified from PCN analysis.

Patients’ PCN experience

To help us understand patients’ experience in terms of care navigation, we examined the functioning of these five main categories of actors in the PCN. The functioning of the patient (a); GP practice (b); informal network (c); experts (d) and additional services (e) were investigated in terms of their roles and responsibilities.

a) Patient: Self-care, disease management and assertive communicator

The interviews showed a strong sense of awareness among participants in terms of their own responsibility as a patient. Interviewees (n=7) pointed out how their own actions contributed to their health (physically) and well-being (mentally). From the interviews, two distinct types of behaviour emerged: actions undertaken to remain as healthy as possible (self-care) and measures taken to control and manage one’s LTCs (disease self-management).
Another element that emerged (n=3/7), was the need to find activities that were possible or adjustable to the interviewees’ LTCs. One participant in particular found this a struggle.

“[…] go to the gym at least three times a week. And do euhm, we do aqua aerobics as that is all I can do, I can only do things in the pool. Because, because anything else is not good for arthritis. So yes, that’s mainly what we do to stay healthy and try to eat healthy.” (pp2)

Two patients disclosed a mental health issue (i.e. depression). However, all interviewees spontaneously stated the importance of self-care in terms of mental health (well-being), sometimes (n=2/7) even if that meant potentially going over their physical limit.

“[…] my responsibility is obviously to keep as healthy as possible, mentally and physically.” (pp6)

Self-care behaviour also included seeking help from the actors in the PCN to, for example, prevent worsening of the situation.

In relation to disease self-management, interviewees emphasised their responsibility in terms of medication adherence, attendance of appointments and daily monitoring of their conditions. Depending on the LTCs participants were diagnosed with, disease self-management and self-care sometimes overlapped and at other times challenged one another. Based on experience, participants developed their own personal ways to practically manage their LTCs and the people involved in their PCN. The use of diaries to keep track of appointments was present in all interviewees (n=7). In addition, some (n=2/7) kept a log of the reason and outcome of appointments as well as their medication.

“Diary and yeah I’ve various things on my computer, like I have a medication list knowing what the medication is for […] I have, every time I go to the GP or go to the doctor or go to the to the hospital, I’ve a list of every time I’ve been. Because often when you go they’ll say to you ‘and when did you last do this?’ and I was thinking I’ll never going to remember so I actually got a log, I started it in 2008, every appointment I’ve ever been to.” (pp2)

Occasionally (n=2/7) patients mentioned that they felt as if they were not given the tools to keep track of their health and/or care. “You know all this business with that they said they gonna let, you can access your medical record? But you can’t!” (pp4).

The third main activity that arose across interviews was the patients’ need to be assertive, determined and proactive.

b) GP Practice: Gatekeeper and general monitor

GP practices were reported by participants, both in the interviews and questionnaires, to hold a central position in their PCNs. The interviews revealed that this central position was the result of and strengthened by two main roles: the GP’s ‘gatekeeper’ role and their function as a general monitor of patients’ health.

All interviewees discussed the process of referral through general practitioner (GP) practices, and the GP in particular. Access to different (health and social care) services in primary, secondary and sometimes even third sector care was gained through the GP. Exceptions to this were patients (partly) choosing to take the route of private care (n=2/7), but even then the GP was often asked for information on services that could be approached.

“Yes, everything has to go through the GP, well not the dentist, but everything else goes through the GP surgery.” (pp2) “I got in from our local general practitioner, a list of companies offering private auxiliary care help.” (pp6)

Apart from being the figure in charge of referral, providing access to other parts in the care system, the GP practice was also seen as the place to monitor patients’ general health. General check-ups were often scheduled ahead (e.g. every six months) to keep an eye on patients’ LTCs such as diabetes. Disease specific follow-up (if needed) did however not fall under the responsibility of the GP practice (see section on experts) according to the study participants.

c) Informal network: Day-to-day support

Drawing on the interview analysis, the informal network was reported to be the main source for patients’ day-to-day support. Depending on its structure (i.e. solely family and friends or also including the wider community), roles and responsibilities of informal actors were shared differently and divided among those involved.

“PP: […] We are lucky at our bowls club because we have a restaurant and we have a bar, you know so it is very convenient. And this to me is that sort of care in the community is where people look out for each other you know?” (pp1)
Day-to-day support mainly involved practical and emotional support. Practical support, such as transportation, was often mentioned (n=5/7) when discussing the importance of family and friends.

“Sometimes use a friend of church for attending the doctor at surgery when I haven’t been able to drive myself […] I have an address book and I try not to bother the people with surnames starting with ‘A’ too frequently (laughs). Which today we will stick the pin in the ‘W’s’ or the ‘S’s’ or the ‘C’s’ or... you know.” (pp6)

Secondly, friends (and sometimes the wider informal network) were a source of information. Information and advice was in particular sought in relation to ‘connections’ friends might have access to and the patient (currently) did not.

“I don’t wanna bother them with things they can’t necessarily answer. I mean if effectively it’s a medical problem you need to see a doctor, don’t you? You don’t ask them... well apart from my friend whose daughter is a doctor so that sort of helps.” (pp2)

Thirdly, family and friends played an important role in emotionally supporting patients by for example being an outlet to talk through acute episodes in LTCs or take their mind of the situation.

“Okay they haven’t got a title as such, but yeah without yeah, without partner and children yeah I don’t know if I would have actually got through the mental rather than the physical sort of thing.” (pp7)

Lastly, immediate family and partners were frequently mentioned to provide informal (social) care. Informal actors often were the ones mentioned under the category ‘other’ SOCC.

“Euhm, feeds me, I think the other aspect is that euh general hygiene of euh washing, ironing clothes and things like that [...] and euh, I mean general, generally helps me and I imagine she helps me more than I help her.” (pp6)

d) Experts: Condition specific needs
The type(s) of experts involved in a PCN was dictated by the type of LTCs patients were diagnosed with. The role patients perceived experts to have, however, largely remained the same regardless of their specialism. According to the interviewees, specialists at the hospital were a source of disease specific testing/monitoring and information.

“I have to go and have my heart check and see that I’m alright. And I spent a lot of time in the hospital I know my way around there as well. You know (laughs) because I have to go to the heart clinic, the chest clinic, the blood place and then anything else. I mean I am forever... X-Ray, I mean you know so yes I know the hospital quite well.” (pp1)

e) Third sector, private care and organisations
The fifth and final group that arose from the data was care provided by organisations, patient groups, etc. Third sector and charity organisations generally comprised services that were used as ‘substitutes’ to health service care or ways to support needs that were not addressed elsewhere. As such this group reflected a personalised addition to the PCN of patients with multimorbidity in accordance to their needs. Services included gardening and companies specialised in transportation for disabled patients.

Apart from substituting health service care, private care was also sought by patients that wanted timely advice or care.

“And sometimes I, the person that I’ve seen, there’s a private physio, he’s, if I want it done quickly.” (pp2).

DISCUSSION
On a general level, our results suggest that care networks are highly complex, spanning multiple institutions and including formal as well as informal stakeholders. In all settings, face-to-face communication plays a big role, and patients’ communication strategies significantly contribute to successful navigation (rather than the system being accommodating of patients regardless of individual characteristics). Communication with, and between, providers constitutes the biggest challenge in care navigation.
Most importantly, our results show that the task of building, and subsequently navigating, one’s PCN rested mainly on patients’ shoulders. Certain factors were found to hinder and others to facilitate effective PCN navigation. From the interviews, time since diagnosis appeared to be an important factor influencing PCN navigation. It was suggested that (unless the person had a medical background), the first LTC could lead to more concerns and difficulties for navigating the system than additional LTCs. Many had learned to find their way around their PCN over time but this did not necessarily aid navigation when difficulties were faced for the first time. Patience was often mentioned to be an important asset for PCN navigation: for example, time spent in the waiting room when attending an appointment was found to be unpredictable.

The major factor leading to a satisfying navigation experience was found to be patients’ assertive, determined and proactive approach. This approach was also needed for patients to find information. Patients felt that information was often spread out and they found it difficult to identify where to look for answers or solutions. A proactive approach was needed to effectively and efficiently navigate a PCN that was made more complex by the design of the wider care system. The system, for example, did not always allow for patients to see the same provider. The way the care system was set-up required participants to persevere in their navigation and deal with a number of complex barriers to accessing services, which could add frustration. Many times patients felt they were sent ‘backwards and forwards’ across the system. The finding that quality of care was essentially dependent on the determination and ability of the individual patient may lead to inequitable care. Those with less determination and poorer organisational skills appear to receive worse care. Technology solutions must aim to fulfil these coordination functions, to ensure care is equitable for those who need it, not just those who ask loudest.

According to patients, the different parts of the care system formed separate entities. Smooth communication and interaction among the different parts of the care system was found to lead to more satisfying navigation experiences. However, for many interviewees it remained unclear whether this actually took place. Participants relied on their assumptions as well as their experience to judge this. On the level of provider-provider communication between colleagues, referral was mentioned as an indication that providers were interacting (e.g., receiving copies of letters sent between providers), and was highly valued by patients. With an apparent limited crossover of information between professionals, it was frequently the patients’ task to bridge and connect the different parts of the system. The willingness and ability to do so were, again, found essential for successful navigation. PCN navigation was reported to be facilitated by a good patient-provider relationship. Whilst seemingly primarily reliant on the patients’ proactive effort, this also depended on the providers’ people skills. Poor patient-provider communication sometimes undermined patients’ trust in the provider and led to a decision to seek care elsewhere. Providers’ people skills were also found to contribute to provider-provider communication. Two levels of provider-provider communication were identified: interaction with colleagues within the same setting and communication between colleagues across settings. Again, mixed experiences were mentioned depending on patients’ assertiveness and providers’ communication skills. Interestingly, existing technology largely focuses on the management of single diseases; for older adults with multiple LTCs to benefit from technology that supports care navigation (e.g., mobile apps, or web-based logging solutions) an integrated approach that takes into account the complexity of the situation of the individual, how they manage their conditions, and seek to involve other stakeholders is required.

**LIMITATIONS AND FUTURE WORK**
There are some limitations and opportunities for future work that arise from this study. Most importantly, the outcomes of our mixed-methods approach to requirements analysis needs to be further validated by putting our findings into action, i.e., designing and implementing a care navigation tool to support older adults with multimorbidity. Furthermore, future work needs to consider the nature of our findings: questionnaire data were obtained from participants residing in England, and follow-up interviews were carried out with geographical restrictions, suggesting that findings need to be interpreted in this light, and need to be reproduced on a national or international level to account for differences between care systems.

**CONCLUSION**
This study stands at the intersection of care and technology, understanding the experience of care navigation for older adults with multimorbidity, as a step towards building technology to facilitate this process. We demonstrate that a mixed-methods approach can deliver insights across the breadth and depth of the care navigation process and outline complexities that need to be considered by both researchers and designers. Moving beyond care navigation, the detailed level of insight provided by Social Network Analysis and Framework Analysis highlights one of the core challenges for HCI research in healthcare settings: while people see potential in the application of technology to care, they first and foremost want better care.

**MULTIMEDIA APPENDIX**
<Multimedia appendix 1: questionnaire>
<Multimedia appendix 2: interview schedule>
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