Study Protocol

Experiences of older primary care patients with multimorbidity and their caregivers in navigating the healthcare system: A qualitative study protocol

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Abstract

Background: Patients with multimorbidity must bear not just the burden of their illness, but also the burden of treatment which is, in part, induced by their interactions with the healthcare system. The need to shuttle between different healthcare institutions and multiple healthcare providers can make navigating the healthcare system challenging, and this may be even more so for older patients with limited resources and support.

Objectives: Few qualitative studies have explored the experiences of patients with multimorbidity in navigating the healthcare system. This study will explore the experiences of older patients with multimorbidity and their caregivers as they navigate through the healthcare system. We aim to arrive at a better understanding of patient experiences of possible gaps in the continuity of care and how the current system can be modified and adapted to better address the needs of older patients with multimorbidity.

Method: Semi-structured, in-depth interviews will be conducted with purposively sampled older patients with multimorbidity, aged 60 and above seen in primary care, together with their caregivers. Interviews will be transcribed verbatim and analysed by the study team using inductive thematic analysis.

Conclusions: Our study seeks to explore the navigational experiences within the healthcare system for older patients with multimorbidity in an Asian, multi-ethnic society. The findings will be shared with decision-makers in the healthcare setting in order to improve patient care for this population and ultimately maximise their positive health outcomes, and will add to better understanding how the burden of treatment arising from navigational challenges within the healthcare system may be reduced for older patients with multimorbidity.

Keywords

Multimorbidity, navigation, older patients, qualitative, healthcare system, study protocol

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Introduction

Multimorbidity, the co-occurrence of multiple chronic conditions in an individual, is a growing public health challenge.[1] Current literature reports that patients with multimorbidity experience psychological and functional challenges in the management of their multiple chronic conditions[2] and a poorer quality of life.[3] They often traverse the full realm of the healthcare system, including primary, secondary and tertiary care, and have to navigate multiple appointments at different healthcare institutions, facing challenges such as lack of coordination between healthcare providers, and conflicting recommendations from different healthcare professionals.[3–6] As a result, the care they receive is often fragmented, which can result in confusion about treatment plans and polypharmacy, as well as increased treatment costs.[4,7] Patients with multimorbidity thus have to deal with not only the burden of their illness, but also with an expanding burden of treatment.[7] This burden of treatment, inadvertently imposed by the healthcare system and attending healthcare professionals, can significantly impact patients' capacity to cope with their medical conditions, on top of their other life demands.[8]

Among the difficulties patients face is access to and navigation through the healthcare system.[5,6,9–12] Rein described navigation of the healthcare system as 'the process(es) by which patients and/or their health caregivers move into and through the multiple parts of the healthcare enterprise in order to gain access to and use its services in a manner that maximises the likelihood of gaining the positive health outcomes available through those services'.[13] For seamless navigation of the healthcare system, patients should experience minimal barriers across all phases of the healthcare continuum such as financial and access barriers, communication and information barriers, medical system barriers and emotional barriers.[14]

Navigation may present particular challenges for older patients with multimorbidity as they have to manage multiple chronic conditions with multiple healthcare providers in different settings.[15] In Singapore, it is projected that one in four adults will be over 65 years old in 2030, and many of them will have multimorbidity.[16] Existing literature surrounding healthcare navigation is mainly focused on the Western populations.[17–19] Studies on the perspectives of patients with multimorbidity navigating the healthcare system has never been explored qualitatively in Singapore. The value of patients' experiential knowledge and expertise in healthcare is increasingly recognised by policymakers, service providers and researchers in providing new angles and perspectives to address current issues and challenges.[20,21] Thus, exploring patients' and their caregivers' interactions with the healthcare system may bring valuable insights into how they navigate the healthcare system between different providers, different settings and at different times for their care needs.

Aims and objectives

This study aims to explore how older patients with multimorbidity navigate through Singapore's healthcare system either alone or with their caregivers.

The primary objective of this study is to understand the experiences of older patients with multimorbidity when they navigate through the healthcare system. Secondary objectives are to identify the barriers and enablers in navigating the healthcare system from the perspectives of older patients with multimorbidity, in order to provide insight into how the current system can be modified and adapted to help them.

Methods

Study design and conceptual framework

This is a qualitative descriptive study[22,23] for understanding a desired phenomenon with a focus on the 'Who, What, Where, and Why' of the experience.[24]

The study will draw on the principles of Minimally Disruptive Medicine (MDM)[8] to guide our understanding of the challenges patients with multimorbidity face. In 2009, reflecting on patients' struggles with managing the work of being ill, May, Montori and Mair called upon clinicians to practise Minimally Disruptive Medicine, a patient-centred approach that seeks to reduce the burden of treatment on patients.[8] MDM, a new philosophy of care, aimed to address structural non-compliance, which was a growing problem in the face of multimorbidity. Structural non-compliance occurs when patients with multimorbidity fail to adhere to their treatments not by choice, but because the way the healthcare system is organised places too much workload on them to practically enact that work.[8] The workload imposed may in fact outweigh their capacity of handling the load. This would impact on the ways in which they navigate the healthcare system to manage their various conditions. MDM recognises these workload-capacity imbalances in patients with multimorbidity and proposes that clinical care has to be fitted into the patient's context, so as to offer minimal disruption and maximum support. The principles of MDM have been strongly advocated in clinical settings[25,26] and a discussion aid has also been developed to elucidate and share insights about patients' capacity to enact the treatment plan for clinical use.[27] The present study advances knowledge about how existing psychosocial, cultural, economic and medical complexities may affect patients' navigation of the healthcare system in Singapore, as well as how navigational experiences and challenges may contribute to patients' burden of treatment.

Setting or context

The healthcare system in Singapore is a combination of public and private practitioners. Primary healthcare is provided by 20 polyclinics (with over 300 doctors) supported

by the Ministry of Health and about 1700 private clinics (with over 2,500 doctors) run by general practitioners (GPs).[28] Despite the preponderance of private GPs, a majority of patients with chronic conditions prefer to visit the polyclinics as they are heavily subsidised through national healthcare schemes.[29] Consequently, the 20 polyclinics manage 52% of the demand for chronic disease management.[30]

Patients in Singapore are at liberty to choose among a variety of healthcare providers, depending on their needs, preferences, accessibility, resources and other personal reasons. However, this wide array of different healthcare providers can impose challenges in ensuring continuity of care for patients who shuttle between different healthcare providers.

Sampling of participants

The interviewees will be patients aged 60 and above with three or more chronic conditions who are being followed up at least once a year at a polyclinic. The caregiver interviewees will be primary caregivers of the participants who are willing to participate in the study.

Purposive sampling using maximum variation will be used to ensure heterogeneity in participants' ethnic groups, socioeconomic backgrounds and ages. We will recruit participants who can converse in English, Mandarin, Malay or Tamil for the interview, agree for the interview to be audio recorded, and must not have been diagnosed with cognitive impairment. As the study seeks to better understand the experiences of patients with multimorbidity when they traverse the healthcare system, patient interviewees must also be under follow-up from more than one healthcare institution.

Recruitment of participants

Eligible patients will be referred by healthcare providers to the members of the research team when they visit the clinics for their appointments. Referred patients who agree to be contacted will be screened via telephone call to assess their eligibility for the study. Caregiver participants will be referred by the patients themselves, or by the healthcare providers in the event that they are present at the participating patient's appointment. Records will be kept of the number of participants who enrolled but later withdrew from the study.

If a potential participant agrees to take part in the study, time and date for the interview will be arranged at his or her convenience. Consent taking will only take place after detailed explanation of the study. Potential participants will be given sufficient time to think and ask questions before joining the study. The study team estimates a maximum of 20 patients and 20 caregivers to be recruited into the study based on recommendations by methodological scholars.[31–33] However, the study team will periodically re-assess whether it is necessary to conduct further interviews given the difficulty of determining data sufficiency within a set sample beforehand.[34] Conversely, the recruitment of participants may end earlier when all members of the study team agree that adequate data have been obtained and data and thematic saturation have been reached.[35] Iterative purposive sampling to achieve a reasonable diversity of target participants will occur in tandem with ongoing analysis, until no new major themes are identified in the data, at which point thematic saturation is considered to have been achieved.

Data collection

A brief questionnaire on demographics will be administered at the start of the interview to collect the participant's socio-demographic information and medical history (Online Appendix 1). This will be followed by a semi-structured interview lasting about an hour, which will be conducted in English, Mandarin, Malay or Tamil by a member of the research team. A secondary interviewer from the team may be present to assist in taking field notes and to support the primary interviewer. ESL, a family physician and primary care researcher with a doctorate in family medicine, PSSL and EALC (research fellows) and SXQ, HLK, EALC and GM (research assistants) will be involved in conducting interviews and performing data analysis. YYD, MS and JVA will provide guidance and input on the execution of the research design and analysis process as experts in gerontology, mental health and qualitative research respectively.

Patients and caregivers will be interviewed separately. Research team members conducting the interviews are trained in qualitative study designs and will have no prior relationship with the participants. Interviews will be conducted in a private and conducive location in the clinic or at participants' preferred location. Field notes will be taken before, during and after the interview to highlight significant information such as non-verbal cues, which will support later analysis of the transcripts.

The interview guide has been designed a priori with reference to existing literature and discussion among research team members, using primarily open-ended questions to elicit as much information on the participant's experiences with navigating the healthcare system as possible while having the flexibility to generate new information at the same time. The areas of navigation which are of particular interest are 1) Physical navigation – getting from one place to another, knowing where to go, barriers and facilitators to getting to the physical appointments, 2) logistical navigation – appointment tracking and management, medication management etc. and 3) information access – whether patients are able to gain access to the resources they need for their healthcare needs.

The questions may be modified over the course of study, using an iterative process guided by the content of previous interviews. In accordance with accepted qualitative

Table 1. Interview guide for patients.

1. Tell me about your experience living with all these different conditions
2. How do you manage the appointments of all your different conditions?
3. Can you share with us how your last visit in the polyclinic was?
4. Tell me about the best visit to the polyclinic or hospital that you have had?
5. Tell me about the worst visit to the polyclinic or hospital that you have had?
6. Can you tell us your experiences being referred from one department to another/hospital to polyclinic/ polyclinic to A&E?
7. Do you think the staff in the clinics and hospitals who take care of you communicate the information about your treatment and health condition to each other?
8. How do you usually feel after your appointment?
9. Have you ever encountered situations where your appointment has been changed?
10. Have you ever missed an appointment? What happened?
11. How do you find out information about the clinics or hospitals that you visit?
12. Do you have any suggestions on how the current healthcare system can be improved?

research practice regarding semi-structured in-depth interviews, the specific questions in the interview guide may be modified and adapted during the course of the interview in order to probe more deeply into areas of particular interest within the overall research question.[31] The questions to be used to guide the patient interviews are listed in Table 1. Similar questions are used for the caregiver interviews, with the relevant changes made to adapt the guide for the caregiver. For instance, the first question for caregivers reads: 'Tell me about your experience helping [patient's name] live with all these different conditions'.

Data analysis

Data from the interviews conducted in English will be transcribed verbatim. Interviews conducted in Mandarin, Malay or Tamil will first be transcribed verbatim and then translated into English by a translator. The quality of transcripts will be verified and vetted against the audio-recording for consistency by the same interviewers before moving on to analysis. Thematic content analysis, using an inductive approach, will be used to identify emergent, recurring and salient themes.

The analysis will be conducted by members of the research team trained in qualitative methodology. Initial codes will be derived from independent coding of two to three interview transcripts, and the coding scheme will be iteratively refined by moving between coding and revising the codes, until all members of the research analysis team come to agreement on the coding scheme. This will then be applied to the remaining interview transcripts. Once the coding scheme has been established, relationships among categories will be explored to facilitate raising the analytical level from the categorical to the thematic level in order to make meaningful accounts of the data. NVivo version 12 will be used to help organise and code the data.

The data from patients and caregivers will initially be analysed as one large dataset. A subsequent analysis will study them independently and in relation to one another using dyadic analysis of separate interviews (Eisikovits & Koren, 2010).[36]

Rigour

Rigour in the coding and analysis of the data will be ensured by following the principles of investigator triangulation, such as the use of multiple researchers from different disciplines.[37] Coding of each transcript will be done by more than one researcher independently. In order to ensure validity of the codes, the research team will meet regularly to discuss or suggest changes to the coding scheme until consensus is reached. The multidisciplinary make-up of the research team ensures that different perspectives are taken into consideration, as the team comprises two clinicians (a family physician and a geriatrician) as well as research fellows and assistants from diverse backgrounds who work in the primary care setting.

Ethics and confidentiality

Ethics for the study has been approved by the National Healthcare Group Domain-Specific Research Board (DSRB No.: 2018/00782). Confidentiality and anonymity of the data will be strictly maintained. Potential participants will be given sufficient time to ask questions regarding their participation and decide if they want to participate in the study. Written informed consent to conduct and audio-record the interview will be obtained from the participants either in English, Mandarin, Malay or Tamil by the research team members before the start of the interview. All participants will be given a copy of the Research Participant Information Sheet and Consent Form and provided adequate time to ask questions about the study. Participants will be informed that they can request to skip any question during the interview or withdraw from the study at any time that they wish.

To maintain anonymity, each participant will be identified by a serial number. The interview will be recorded on audio tape with a digital audio-recorder. The audio recordings will be transferred and saved in password encrypted files in an encrypted hard disk or standalone computer, and the original recording on the audio-recorder will be deleted. The source data, hardcopy data and audio recordings will be kept under lock and key. The research data will only be accessible by authorised study team members. Data analysis and presentation of results will be carried out in such a way that no participant can be identified.

Discussion

The expected increase in the number of older adults with multimorbidity in the coming years underscores the need to ensure that they are able to easily access and utilise healthcare services according to their needs, preferences and available resources. Presently, the experiences of older patients with multimorbidity in Singapore and the challenges they encounter in accessing and using healthcare resources optimally has been given minimal attention. This study appears to be the first to use a qualitative descriptive approach for exploring their experiences in depth.

This study will provide insights into how older adults with multimorbidity and their primary caregivers navigate Singapore's healthcare system as well as their experiences dealing with multimorbidity. It may provide solutions to reduce the number of clinic visits, simplify medication regimens and help put into the limelight the hidden costs of healthcare such as transportation and time off work for family members and caregivers. Through this, we hope to provide clinicians and policymakers a better understanding of patients' perspectives and experiences and ultimately use the findings from this study to improve patient care. The findings and recommendations of the study will be relayed to decision-makers within the local healthcare institutions, as well as disseminated in primary care conferences and journal publications.

We will present our findings in accordance to the standards for reporting of qualitative research.[38] Although the design of the study means that findings may not be generalisable to all older patients with multimorbidity in primary care, using such an approach has the capacity to yield authentic, real-world accounts. As such, this study will make a significant contribution to advance our understanding of the contextualised treatment burden imposed on this group of patients and their caregivers.

Authors' note

ESL and GM are co-first authors.

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Supplemental material

Supplemental material for this article is available online.

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