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### STUDY PROTOCOL

# Multimorbidity in middle-aged persons: experiences of

## patients and their health care providers: Protocol of a

## qualitative stakeholder analysis [version 1; peer review:

## awaiting peer review]

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### Abstract

Middle-aged persons with multimorbidity have to take their illnesses into account in their daily work, family and leisure activities. The MuMiA project aims to identify early preventive measures that make it easier for those between 30 and 60 years of age with multiple chronic diseases to manage their illnesses in their everyday lives. An interdisciplinary workshop and interviews with multimorbid middleaged adults and their principal healthcare providers will be used to collect information on the management of care in the contexts of patients' daily work, family and leisure activities. Data obtained in the interviews will be coded inductively and analysed using content analysis. Workshop outputs will be transcribed and evaluated by the authors. This study has received ethical approval from the Faculty of Medicine Ethics Committee of Goethe University (2021-47). The project will generate prevention recommendations that reflect the experiences of middle-aged persons living with multimorbidity and the views of their principal healthcare providers. The findings will be disseminated via conferences and peer-reviewed publications.

### **Keywords**

Multimorbidity, middle-aged, everyday life, qualitative research

### **Open Peer Review**

Approval Status AWAITING PEER REVIEW

Any reports and responses or comments on the

article can be found at the end of the article.

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#### Introduction

Multimorbidity, defined as the presence of two or more chronic conditions in the same person,<sup>1</sup> has become increasingly common in recent years.<sup>2</sup> Although the prevalence of multimorbidity increases with age,<sup>2</sup> over 50% of persons with multiple chronic diseases are under 65 years of age.<sup>3–5</sup>

People with multimorbidity have lower quality of life,<sup>6</sup> make greater use of healthcare services,<sup>7</sup> and have higher mortality.<sup>8</sup> However, the impact of multimorbidity on the everyday lives of patients may be different for middle-aged persons than for the elderly.

Middle age is the time that most chronic conditions appear. To continue to pursue professional careers, raise children, and care for elderly parents, while at the same time wishing to preserve their leisure time, middle-aged persons with multimorbidity have to take the care of their illnesses into account during their daily, sometimes very tight schedules. Healthcare research has not yet focused on the impact of multiple chronic conditions on these life domains.

Our research is aimed at finding out how middle-aged persons with multimorbidity experience the care of their multiple illnesses in the context of their individual leisure time, their families, and their working lives. We will also include the perspectives of their healthcare providers in order to identify obstacles to care in this patient population, and to identify early, preventive measures that patients can take to facilitate the day-to-day management of their illnesses. This study is part of a larger project named MuMiA that aims to improve the care of persons with multimorbidity in the 30-60 age group.

#### Methods

The MuMiA project is a mixed-methods project combining a systematic literature review<sup>9,10</sup> with qualitative research on middle-aged persons with multimorbidity and key players in their care networks (i.e., their healthcare professionals).

#### Study design

This paper presents a protocol of qualitative research on persons with multimorbidity and their healthcare providers in Germany that follows the consolidated criteria for reporting qualitative research.<sup>11</sup>

To capture patients and other key healthcare stakeholders' views across services and professions, we will perform semistructured individual interviews using maximum variation sampling. Data gathered from the individual interviews will be supplemented with information collected from interprofessional focus groups involving key healthcare professionals.

#### Study participants

Participants will be i) middle-aged adults (30-60 years old) that self-report having two or more simultaneous chronic conditions<sup>1</sup> and ii) key players in their Germany-based healthcare networks (e.g., general practitioners, cardiologists, neurologists, physiotherapists, pharmacists ...). Exclusion criteria will be insufficient knowledge of the German language and inability to provide informed consent.

#### Study activities

#### Selection and recruitment

Recruitment of patients will be performed via a flyer distributed to the waiting rooms of health centres (general practices, pharmacies, physiotherapy practices, self-help groups), self-help groups, as well as direct invitation by healthcare providers. Patients will be selected to ensure that differing combinations of chronic conditions are represented.

We will invite healthcare providers to participate via an announcement to be issued in the Institute of General Practice and the University Hospital's internal newsletters, as well as through the Institute's research network (ForN) and personal contacts.

The selection of healthcare providers will depend on the professions that patients, in their individual interviews, describe as playing a substantial role in their care. We aim to recruit at least 15 healthcare providers from a multitude of professions. Since patients will be explicitly asked about the role of their general practitioners, GPs will certainly be among those recruited.

We will provide different options for potential participants to contact the study team if they are interested (i.e., phone, email, post).

Participants will be informed that they will receive compensation of €50 each.

Patients and those of their key healthcare providers that have shown an interest in participating in our study will receive a telephone call in which details of the project will be explained. Questionnaires containing relevant data (e.g., demographics, health-related data (for patients), years in practice (for health care professionals)) will be used to assess eligibility.

#### Informed consent

Before any study-specific activities are undertaken, participants that fulfil the eligibility criteria will be sent the participant information and informed consent forms by email. The forms will include information on the exact nature of the study, what it will involve for participants, the implications and constraints of the protocol, and any risks involved in taking part. It will be clearly stated that participants are free to withdraw from the study at any time and for any reason without prejudicing their future care and without obligation to explain their decision.

Participants will be allowed as much time as they require to consider the information, and will have the opportunity to ask the Investigator, their general practitioner and other independent parties before deciding whether to participate in the study.

Participants providing their written informed consent and persons accepting the consent forms will then sign and date them. Persons accepting the consent documents will be suitably qualified and experienced, and have been authorized to do so by the Principal Investigator (MvA). A copy of the signed Informed consent form will be provided to the participant, while the original signed form will be retained at the study site.

#### Interview and workshop guides

The interview guide will be developed according to the "Manual for conducting qualitative research" by Helfferich,<sup>12</sup> and based on the findings of the literature review<sup>9</sup> and the research questions outlined above. Although the guides will include predetermined questions that the researchers should ask in the semi-structured interviews, participants will also have the opportunity to discuss issues they feel are important. The workshop guide will be developed based on the results of the individual interviews.

#### Data collection

Either TSD, MSB, RB or CS will speak to the participants by phone, after which the interviewers will have no further personal contact with them. Digital technologies will allow us not only to recruit in a different way to usual, but also to collect data and offer participants opportunities for involvement in research without the need for face-to-face contact.

Overall, we aim to conduct 15 in-depth telephone interviews with middle-aged persons with multimorbidity and 15 with key players from their health care networks. The 30-45-minute interviews will be based on the semi-structured interview guides described above and will enable the researchers to find out about the participants' experiences. Interviews will be digitally recorded and transcribed verbatim, and the accuracy of the transcripts checked by the respective interviewers.

Following the interviews, an interprofessional workshop lasting about two hours will take place with the healthcare professionals and be mediated by an independent moderator. The workshop will allow us to deepen and enrich our understanding and provide alternative insights into the information gathered in the individual interviews with key healthcare professionals. It may also help identify opportunities for interprofessional collaboration. Social interaction between participants is expected to result in lively discussion and facilitate the collection of useful and meaningful data. The workshop discussion will be recorded, so that data can be collected synchronously.

The outcomes from the interviews will be presented to and discussed with the healthcare professionals during the workshop. Protocol notes will be taken and the resulting work materials such as flip charts etc. will be documented and evaluated.

#### Data analysis

Data will be analysed using qualitative content analysis and inductive coding as described by Kuckartz.<sup>13</sup> Coders (TSD or RB) will read all transcripts to familiarize themselves with the data. Interviews will be analysed sequentially using inductive coding to provide a working analytical framework. TSD and RB will carry out coding independently, whereby regular discussions on the coded text passages and assigned codes will take place between the coders. Data will be managed using MAXQDA V.18 (Verbi).

#### Data protection

All confidential data will be kept on password-protected computers that are only accessible to members of the research team for ten years. All personal data will be pseudonymized, and personal data replaced by a number and a letter code.

During transcription, audio-recordings will be anonymized, and all identifiable information removed prior to using the software analysis tool. All audio-recordings will be erased after 10 years.

Participants will provide written consent that the interviews and workshop may be recorded and transcribed (only interviews), and that the data may be published anonymously.

#### Patient and public involvement

There will be no patient or public involvement in designing and conducting the study.

#### **Researchers characteristics**

AIG (Q): General Practitioner and PhD (experienced qualitative researcher in the field of multimorbidity and polypharmacy).

TSD (Q): BSc. Public Health, MA. Health Research and Management (experienced in qualitative research, stakeholder analyses, healthcare research focusing on multimorbidity and polypharmacy).

RB (&): Pharmacist (experienced in analysing qualitative data on multimorbidity).

MSB (Q): MSc. Physiotherapy. Health Research and Management (experienced in qualitative research, stakeholder analyses, healthcare research on multimorbidity and polypharmacy).

CS (Q): MSc Public Health and 4<sup>th</sup> year resident of Preventive Medicine and Public Health (experienced in conducting interviews).

MD (Q): MSc Medical management for health scientists. BSc Sport and health in Prevention and Therapy (experienced in analysing qualitative data on chronic diseases).

BM (Q): General practitioner (experienced in qualitative and quantitative research into patient safety and multimorbidity).

MvA (Q): MSc Health Sciences and PhD Medical Sciences (expert in the epidemiology of multimorbidity, and experienced qualitative researcher in the field of multimorbidity and polypharmacy).

## Ethics and dissemination *Ethical considerations*

The research will be conducted in accordance with national ethics guidelines. Approval was granted by the Ethics Committee of Goethe University, Frankfurt am Main (2021-47) on February 15<sup>th</sup>, 2021. Participants will receive an allowance of  $\notin$ 50 each.

#### Output and dissemination

The outcomes of the project will be secondary and tertiary prevention recommendations that reflect the experiences of middle-aged persons living with multimorbidity, and the views of their principal healthcare providers. The findings will be disseminated via conferences and peer-reviewed publications, and will be presented in a patient-friendly format on the website of the Health Knowledge Foundation "Stiftung Gesundheitswissen".

#### Conclusions

This study is the first to gather information on the care experiences of middle-aged adults with multimorbidity, and the key players in their care networks. The project will generate prevention recommendations that reflect the experiences of middle-aged persons living with multimorbidity and the views of their principal healthcare providers.

#### Data availability

Underlying data No underlying data are associated with this article.

#### Extended data

Open Science Framework: Multimorbidity in middle-aged persons: experiences of patients and their health care providers, https://doi.org/10.17605/OSF.IO/M8X69.

This project contains the following extended data:

- Additional file 1\_COREQ 32.pdf
- Additional file 2\_Flyer for the patient interview.pdf
- Additional file 3\_Patient data questionnaire.pdf
- Additional file 4\_Health care provider data questionnaire.pdf
- Additional file 5\_Patient information and informed consent.pdf
- Additional file 6\_Stakeholder information and informed consent.pdf
- Additional file 7\_Interview guide for patients' interviews.pdf
- Additional file 8\_Interview guide for healthcare professionals' interviews.pdf

Data are available under the terms of the Creative Commons Attribution 4.0 International license (CC-BY 4.0).

#### Ethics approval and consent to participate

Ethikkommission des Fachbereichs Medizin der J. W. Goethe-Universität Frankfurt am Main (grant no. 2021-47).

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