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ABSTRACT

Background

Prevalence of people with multimorbidity (PM) rises. Multimorbidity constitutes a challenge to the health care system, and treatment of PM is prone to high quality variations. Currently, no set of quality indicators (QI) exists to assess quality of care, let alone incorporating the patient perspective. We therefore aim to validate and amend a literature-based set of QI from the patients' perspective.

Methods

We conducted eight focus groups (FG) with PM and three FG with patients' relatives using a semi-structured guide. Data was analysed using Kuckartz's qualitative content analysis. We derived deductive categories from the literature, added inductive categories (new quality aspects) and translated them into QI.

Results

We created four new QI. Two QI (patient education/self-management, regular updates of medication plans) were consented by an expert panel, while two others were not (periodic check-ups, general practitioner coordinated care). Half of the literature-based QI, for example assessment of biopsychosocial support needs, were supported by participants' accounts, while more technical domains regarding assessment and treatment regimens were not covered in the FG.

Conclusion

We show that FG with patients and relatives add relevant aspects in QI development, should be incorporated by default in QI development processes and constitute a reasonable addition to traditional QI development. Our QI set constitutes a framework for assessing the quality of care in the German health care system. It will facilitate implementation of treatment standards and increase

the use of existing guidelines, hereby helping to reduce overuse, underuse, and misuse in the treatment of PM.

German Clinical Trials Register: DRKS00015718, registration date: 15th of October 2018

Strengths and limitations of this study

- affected patients and their relatives (who often function as informal caregiver) were questioned in the focus groups
- FG participants from two differently structured regions in Germany representing a wide spectrum of combinations of different diseases were queried
- FG with patients and their relatives (asking about positive and negative experiences with care) seem to be an effective tool to identify quality aspects relevant for QI development

INTRODUCTION

Our society is aging and higher life expectancy is associated with higher rates of chronic diseases. Care for patients with multimorbidity (PM) will evolve into one of our most prominent challenges in the future [1,2]. Multimorbidity is strongly linked to functional limitations, lower quality of life and increase in health care utilization, costs and higher mortality [3,4]. Care for PM is very complex [5] and therefore prone to deficits in quality and major (unintended) interindividual differences regarding the impact of illness and carer performance [6–9]. Generic standards for high quality of care are hard to define due to the infinite number of possible (combinations of) medical problems in PM. Evidence-based standards relevant to PM are urgently needed. As long as the current state of health care cannot be mapped systematically, for example by using a set of quality indicators (QI) specific for multimorbidity, it remains impossible to compare the effects of interventions and health care models to optimize quality or to identify sectors, regions or health care providers needing improvement.

Considering the patients' perspective is even more relevant when dealing with PM. Every decision made concerning risks and benefits of treatments and interventions has to be weighed against individual impairments, comorbidities and gain in subjective quality of life [10]. Prioritization must take the whole range of bio-psycho-social complexities into account and follow principles of patient-centred clinical management and decision making. Views on high quality health care often differ between patients and their health care providers [11] and therefore patients can [12] and must be involved in guideline and QI development [13–16]. Studies show that this is not often the case [14] even though approaches to patient involvement in QI development, e.g. focus groups (FGs), exist and are considered to be of high value [13].

The MULTIqual project aims at the development of a quality indicator set which can be used to evaluate the current state of health care provided for PM and to promote the implementation of treatment standards for future care. We conducted FGs with PM and their relatives to validate and amend a literature- and expert consensus-based set of QI by qualitatively surveying their views on health care quality.

METHODS

The MULTIqual project is a multi-centre mixed-methods project comprising a systematic literature review, FGs, a two-stage expert consensus process and a quantitative survey with PM and general practitioners (GPs). Following the COREQ [17] this paper presents the results of FGs with PM and their relatives conducted in Hamburg and Heidelberg and of the expert consensus on the QI set.

Participant selection and recruitment

We randomly selected and invited GPs to take part in our study. Participating GPs were asked to recruit patients aged 65 and above with three or more chronic conditions that attended the practice at least once in the last three months. PM willing to participate were asked to invite close relatives to take part in the study. Exclusion criteria were insufficient knowledge of German and inability to give informed consent. Patients received an invitation containing study information, a response sheet and a reply envelope. Participants received an allowance of 30€ plus a reimbursement of travel expenses. Participants gave written informed consent for the FGs to be recorded, transcribed and the data being published anonymously.

Focus group guide

Guide development was based on the literature review (e.g., [18]) and the research questions outlined above. As lay persons mostly relate to implicit experiential knowledge when defining quality criteria, we chose to question our FG participants about their own positive and negative experiences with primary health care, changes in their health care needs and experiences due to multimorbidity and their vision of ideal primary care for people like them (see suppl. file 1 for 'patients' focus group guide'). With patients' relatives, the same topics were discussed in respect to the associated PM (see suppl. file 2 for 'relatives' focus group guide').

Data collection

Either JS, CH, AB or KG had spoken to the participants on the phone, but had no other relationship with them. In 12/2018 and 01/2019 we conducted eight FGs with PM (city A =3, city B= 5) and three FGs with patients' relatives (A=1, B=2) using the semi-structured guides described above. Two moderators facilitated the FGs (NJP, JS, KG, AB, CH and TKl respectively) which lasted about two hours. Discussions were digitally recorded and transcribed verbatim by a trained research assistant following designated transcription rules. Accuracy of the transcripts was checked by the respective moderators. In order to protect the FGs participants' identity, names and other identifying details were changed during transcription.

Expert panel meeting

The expert consensus process consisted of two stages: an online rating of draft quality indicators by an expert panel (EP) and an in-person meeting. The EP consisted of representatives of primary care, nursing, practice management, quality research methodology, social work, physical therapy, geriatrics, clinical pharmacology, social medicine and patient representatives. The in-person meeting took place on 1st February 2019. Prior to the meeting the experts had rated the literature-based QI set concerning significance, clarity of definition, possibility to influence the indicator manifestation, strength of evidence and potential risks/undesirable effects using an online platform. The EP discussed and selected a preliminary QI set to be used and validated in the quantitative survey. The EP judged indicators (described below) based on initial analyses of FG material ad hoc during the meeting after a presentation by NJP.

Data analysis

Data were analysed using the qualitative content analysis approach described by Kuckartz [19], following a realistic paradigm [20]. Coders (NJP, CH and JS) read all transcripts to familiarize with the data. Transcripts were broken down into fragments adopting different sizes ranging from part of a sentence to one or more paragraphs in relation to the segment length needed to understand the content and context of the relevant accounts. We created deductive codes representing the aspects of quality described in the literature-based QI set and selected by the EP and inductive codes when new aspects of quality emerged from the data (see below). We then subjected all transcripts to a second round of coding by a different coder. Coding was carried out with constant discussions between the three coders about the coded text passages and assigned codes. To ensure intersubjective reproducibility and comprehensibility [21], the results were presented to and discussed with the interdisciplinary workgroup ‘qualitative methods’ and the co-authors DL (postdoctorate, MD) and MS (professor, MD). Data was managed using MAXQDA 11 (Verbi GmbH).

Identification of additional patient relevant quality aspects

We aimed to supplement the preliminary QI set extracted from a systematic literature review by QI quality based on patient-relevant quality aspects derived from the FG data. A multidisciplinary research team (NJP, CH, KG, AB and JS) allocated subjectively important quality aspects from patients' and their relatives' views to the preliminary set of QI based on the literature review and identified important additional quality aspects where needed. Afterwards the research team transformed the new quality aspects into QI.

Patient and public involvement statement

Patients were involved in the recruitment of focus group participants (viz. their relatives). Patient representatives and representatives of relevant fields (see above) were involved in the rating and selection of quality indicators. Apart from that there was no patient or public involvement in the study.

Researcher characteristics

Researchers' characteristics, beliefs and assumption influence qualitative research and data interpretation. NJP (♀): post-doc psychologist, experienced qualitative researcher (patient involvement in QI development, health care research focusing on general practice). JS (♀): psychologist/junior scientist. CH (♀): medical student. AB (♀): junior scientist, M.A. Health Information Management. DL (♀), KG (♀), JSz (♂), MS (♂): medical professionals, experienced post-doc researchers in the field of general practice and QI development.

RESULTS

Participants characteristics

29 female and 18 male patients aged 65-84 years as well as three female and six male relatives (five spouses/four children) aged 49-78 years took part in five patient groups and three relatives groups

respectively. Nine registered volunteers did not take part, with n = 3 due to acute health problems and n = 6 due to organizational difficulties.

Focus group-based additional quality aspects included into the QI set after the EP rating

Two focus-group based quality aspects were finally supported by the EP and included in the QI set.

Patient education / self-management

Patients consider it very helpful to be informed about their diseases and possible (self-) treatment and management strategies (for example, nutrition counselling). Daily disease management can be supported by specific information on self-management strategies, training in disease-related competencies (for example, measuring the INR value), addressing coping strategies and provision of knowledge for the patient.

> *"I took part in a course in [city] and have been monitoring my 'Quick' [prothrombin time] myself for over 20 years and I have a book and also keep a record. And I always took it with me to the hospitals and the doctors were amazed that they could see exactly how I did it and how I tested my 'Quick'. […] And I always write it down and then I dose the medication myself. No, I am still grateful to the doctor for giving me the tip that I can do the course how to measure my 'Quick' on my own […]."*
>
> *(city B, patient focus group A, paragraph 162-166)*

Regular updates of medication plan

Patients report to have been provided with medication plans and consider it very important for them to be up-to-date especially when taking a high number of different medications or when medication is prescribed by specialists. Some patients always have copies of their medication plan at hand in case of an emergency and it would be considered helpful if this plan was accessible electronically on the health insurance card.

> *"This is also from the GP, right? It's a medication plan. So you know when to take it and so on. One should know that. But also that you can show it, if someone asks: 'What are you taking?' Oh god, yes, what am I taking? What's it called again? It just changed again, hasn't it? Well, I know it, but it's also good for the other doctors if they have something printed and to be able to see exactly what she needs, what she takes, how often and when […]. So, it is very pleasant when GPs do something like that. Gives you a certain amount of security."*
>
> *(city A, patient focus group B, paragraph 251-253)*

Focus group-based additional quality aspects not included into the QI set after the EP rating

Two other indicators were not supported by the EP and not included in the final QI set.

Regular check-ups

Patients with chronic diseases see a need for regular check-ups as it would allow for early detection of health deterioration and they know these procedures from the disease management programmes, e.g. for diabetes or COPD. They value the regular contact with the GP at fixed appointments.

> *"[...] if you take these medications regularly and then say: "We'll have a general check-up once every two years" – I think that's not enough. I think it should be every year. The status should be checked once in a while, if I'm taking these pills regularly."*
>
> *(city A, patient focus group C, paragraph 97)*

General practitioner coordinated care

Patients appreciate the GPs to coordinate their care which involves for example writing referral letters for specialist visits (and the GP receiving medical reports), having a network of specialists at hand, planning preventive measures and keeping track of medications and their interactions and side effects. Patients who describe their relationship with their GP as trusting, want all information on their health care to converge at their GPs' practice.

> *“[...] when the diagnoses are made and the GPs know what's going on, then they should actually act as a control center and have the possibility to coordinate everything.”*
>
> *(city A, patient focus group A, paragraph 264)*

> *“That's a given in our practice. He always wants to give you referrals because he wants to have doctor's letters. Otherwise he says he doesn't have an overview. And I think that's very, very good.”*
>
> *(city B, relatives' focus group A, paragraph 66)*

Literature-based quality aspects supported by focus groups

Table 1 gives an overview of quality aspects identified in the literature review and supported by both FGs and expert consensus and shows supporting quotes from the FGs. Descriptions of categories shown table 1 follow below.

Table 1: Quality aspects identified in the literature and supported by focus groups and expert panel ratings

Patient-related factors	Assessment of biopsychosocial support needs	“So for me, I would like to see myself not only as a body, or only as organs, but as a complex human being. That’s very important for me, […] this union of body, mind and soul." (*city B,* patient focus group A, paragraph 70) “This is certainly an aspect that the doctors should [...] actually take a closer look at again: What is the situation at home? Does the person need support? Do we have to organize something?” (*city B,* relatives' focus group A, paragraph 91)
	Involving partners, family and caregivers	“Perhaps this could be discussed in a phone call with relatives, so that I am informed about the current situation, what is pending or how the medication maybe, yes, what I have to pay attention to as a caring relative and, as I said, if this is okay for my mother, as I know that she is not informed at all.” (*city B,* relatives' focus group A, paragraph 174)
Physician-patient-interaction	Shared decision-making and mutual agreement on treatment goals	“A doctor's sole decision: (.) "Do this or that" - if the patient doesn't agree, it is pointless (...). He won't do it anyway. (..) And that's why I think that those issues really need to be discussed together. And determined together what is possible for the patient. Not everything is possible." (city A, patient focus group A, paragraph 468) “[...] we discussed it [...] at eye level in a VERY thorough conversation, so that we decided on the therapy regimen together, which I follow, and use take control of the disease." (city A, patient focus group A, paragraph 21)

	Information about medication and potential benefits and harms of treatment	“It's important to me [...] that I get information in an [...] understandable way about what is going on with me and how this could be treated.” (city A, relatives' focus group A, paragraph 357) “And then that in some cases he may explain the disease. Not the disease, but the measures, that's the way I wanted to put it. But then we come back to the time factor again. But in some cases, as I said, it is done this way. So that you get a little more time and get information about what is actually going on and what you can do about it. Or against it.” (*city B,* relatives' focus group B, paragraph 98) “But it’s just that when I get pills and it says this and that and you don’t even know what it’s for. […]” (*city B,* patient focus group C, paragraph 43)
	Medication review and documentation of adverse drug reactions	“Especially in the case of multiple chronic diseases, I find it extremely important that the general practitioner explains to me that the drugs are compatible, that there is no interaction or that it is possible that they will cancel each other out or even worsen the condition, as in the case of my mother [...]”(*city B,* relatives' focus group A, paragraph 69) “I also consider close monitoring of drug effects and side effects important. Because there are side effects that one does not even register, which develop so insidiously. So it's a good thing that experts with their backgrounds check for possible side effects and say: “Watch this, something is happening to you, that doesn't fit in or it's a side effect”.

		Because I only read the package insert when I really have something and suspect a side effect. I do not read them in advance. Because then you don't take the drug." (city A, relatives' focus group A, paragraph 357)
	Written treatment plan	"I packed a little something from my management. I don't know if you know anything like that, here is a blood sugar diary for people on insulin. This is from the diabetes clinic. It contains all my data, every record, both blood sugar levels and blood pressure and then the insulin dose. And I also check my weight and write it down here, so I always keep everything together. And I take this to my general practitioner as well as to the other doctors, for example to the eye specialist. And I think that's good." (city A, patient focus group A, paragraph 167-168)
Context and Organizational Structures	Comprehensive care documentation	"I think [...] to keep an overview of the attending specialists is actually very important. Because [...] when I go to the eye specialist or ear, nose and throat specialist, and the GP doesn't even know this, and usually doesn't get a medical report from them either, then he is actually missing out […] on important information. I could have glaucoma, or whatever. And he doesn't even know about it and he doesn't even know what kind of medication you might have to take. […]" (city A, patient focus group A, paragraph 466)
	Training programmes addressing	"Whereby I have to say with my GP's joint practice, you can't complain. So there are two [employees], I think, they are still trained nurses. That's how long they've been at it. They are REALLY competent. And I'd say they already

	management of patients with multimorbidity	have a certain diagnostic instinct. They can tell when someone comes in with swollen eyes, whether it's just a flu-like infection or a real flu, that he should perhaps be isolated.” (city A, relatives' focus group A, paragraph 108) “Well, of course we have the problem that we have more and more elderly people who are sick, and have multiple diseases. And we have fewer and fewer GPs. So, I think it would be a very good care model if we had, for example, registered physicians who specialize in geriatrics. I think it would be a good care model if we had general medical training, with additional specialization, for example in mental health. I would prefer geriatrics and that these doctors with such training, who also have many, many or mostly older patients, are given more time. That perhaps, there are also these reference numbers, what they can charge. Because, we have to get there, because there are more and more elderly people, that they would get the possibility, the aspect of time and if it is only five minutes. Five minutes is a lot per patient. But that is of course an idle wish [...]” (*city B,* patient focus group A, paragraph 85)

Assessment of biopsychosocial support needs

Patients expressed a need for the GP to have a holistic view on the patient's health problems and needs. They underlined the importance of not only seeing and treating physical symptoms, but also the overall picture of medical and psychosocial aspects of the patient's situation. They consider it important for the GP to have at least basic information on the patient's background and personal history. Sometimes house calls can be necessary for a realistic judgement on biopsychosocial support needs for example for elderly people with beginning dementia.

Involving partners, family and caregivers

Relatives of people with multimorbidity often appreciate the GPs' willingness to communicate with them and support them in the process of giving care. Support and advice are often desperately needed by informal caregivers of persons with multimorbidity, especially if dementia is an issue. GP's awareness of informal caregivers' problems and concerns is important and could for example be addressed by offering consultation hours for relatives and other informal caregivers.

Shared decision-making and mutual agreement on treatment goals

Shared decision-making to find a customized treatment approach for individual patients is highly appreciated by the FG participants. Communicating, informing and deciding on treatment regimens and goals on a par with the patient are seen as essential for increasing adherence and patient satisfaction. Patients value the freedom to set their own priorities and make decisions based on their values and preferences concerning their health and health care behaviour. They appreciate their GPs supporting them in this approach and the autonomy this respect gives them.

Information about medication and potential benefits and harms of treatment

Our FG participants did not differentiate clearly between information and advice on their diagnosis, disease or condition and risks, medications (for example indication, dosage and interactions) or non-pharmacological treatments and their benefits and potential side effects. They emphasize the importance of detailed and comprehensible information on all these aspects. Either way, some stated not be interested in very detailed descriptions of potential risks and side effects. The amount of information given must be tailored to the patient’s needs even though these consultations might need more time than usually budgeted.

Medication review and documentation of adverse drug reactions

Medication reviews are highly acclaimed by the FG participants. Patients and their relatives wish for the GP to check for interactions regularly especially with medication prescribed by others and over-the-counter (OTC) drugs. They expressed criticism of the high numbers of prescribed drugs and low engagement of health professionals to actively inquire about drug-related problems and to search for highly tolerable medications. Patients focus less on the thorough documentation of adverse drugs reactions than on their monitoring and handling. They wish for the GP to detect signs of adverse effects and monitor them for example through regular follow-ups.

Written treatment plan

FG participants’ recognize the value of written treatment schedules that include overviews on scheduled health care appointments plus instructions, e.g., whether they have to appear with an empty stomach for bloodwork. They emphasized the advantages of automated recalls systems. Another focus was on recorded treatment protocols, e.g. keeping a blood pressure journal or a diabetes log book containing measured values and other relevant parameters. Patients proposed using digital solutions for facilitating care coordination between different providers.

Comprehensive care documentation

The vast majority of the FG participants consider comprehensive care documentation as a vital part of high quality care, emphasizing importance of the exchange of information on diagnostic testing or examination results and prescribed medication, giving the GP the opportunity to coordinate care and consult the specialist about the patient’s treatments. Patients report that the responsibility for this exchange is often in the patients’ hand, being the ones to take care of specialists’ letters being issued to the GP. Under the premise of data security, patients would support a digital exchange of doctor’s letters, but sometimes doubt the ‘digital competencies’ especially of the older generation of physicians.

Training programmes addressing management of patients with multimorbidity

Patients put emphasis on the competencies of the practice team. For medical assistants this means for example being experienced in taking blood samples or giving shots. Another aspect is the ability to triage patients according to the severity and urgency of their treatment needs. GPs should engage in continuous medical education, be up-to-date on actual research results and technological advances. Participants valued additional training in the field of geriatrics or psychology and proposed regular supervision and peer consultation for complex problems in multimorbid patients.

Literature-based quality aspects not supported by focus groups

Table 2 gives an overview of quality aspects identified in the literature review and supported by the EP but not accounted for in FGs. As this paper focuses on the FG result, these quality aspects are described extensively elsewhere (manuscript in preparation).

Table 2: Literature-based quality aspects not supported by focus groups

Patient-related factors	Screening for depression
	Proactive pain assessment
	Monitoring of pain management
	Addressing financial support needs
	Quality of life assessment

	Assessment of symptom burden
	Establishing patient preferences
Physician-patient-interaction	Identification of patients with multimorbidity
	Assessment of treatment burden
	Monitoring adherence to treatment
Context and Organizational Structures	Assigning responsibility for coordination of care

DISCUSSION

Main results

By asking PM and their relatives in FGs about their experiences with primary health care we derived four new patient-relevant QI to date not represented in guidelines or the literature on quality of care in multimorbidity. Out of these, two QI concerning regular updates of written medication plans and patient education and fostering self-management were supported by the EP. On the other hand, regular check-ups and GP-coordinated care were not supported by the EP. Half of the literature-based QI, for example assessment of biopsychosocial support needs, establishing patient preferences and shared decision-making, were supported by participants' accounts, while more technical domains regarding assessment and treatment regimens were not covered in the FGs.

Strength and limitations

To obtain a comprehensive picture of aspects of quality of care from the affected persons' point of view we asked not only patients with multimorbidity, but also their relatives (often informal caregiver) in separate groups. FG participants were recruited in two very differently structured regions of northern and southern Germany and represent a wide spectrum of combinations of different diseases. We therefore assume that our results might be cautiously generalizable to PM in primary care all over Germany.

Reflecting and evaluating own experiences is dependent on representation of different perspectives, lived experiences and group interaction, and must be fragmentary, as participants were lay persons regarding health care (quality). Therefore, it did not seem feasible to ask the participants to propose QI. Instead, we focussed on positive and negative experiences with primary care and derived patient-relevant QI indirectly. As many accounts can be matched to QI derived from the literature and half of the newly developed QI were supported by expert consensus this methodology seems to be plausible and practicable.

Although the questions focussed on experiences regarding the related PM, the results from FGs with relatives show that for some participants it was difficult to focus on their role as (caregiving) relative. Many participants referred to their own health care experiences being affected by multiple conditions themselves, which reflects the spectrum of issues and challenges in the field as the prevalence of multimorbidity increases in older age [22].

Discussion of results and comparison with existing literature

Since 2016, patients enrolled in statutory health insurance in Germany have a right to be provided with a recorded medication plan if they a prescribed at least three different long-term medications, which is very much appreciated by persons with multimorbidity in our study and elsewhere [23]. There are plans to incorporate these data into the electronic health card to allow for a standardized digital exchange of this information of these data between providers [24,25]. Despite preferring a written medication plan and stating the problem of insufficient communication between prescribing physicians, participants of our FGs judged this incorporation ambivalently as they saw problems concerning data safety and confidentiality [26] as well as (older) GPs digital literacy.

PMs wish for patient education, fostering of self-management and periodic check-ups might arise from their experiences with patient education and regular control of, e.g., blood values, respiratory function and blood pressure during the structured disease management programmes (DMP, e.g., [27]) that many patients with diabetes, COPD or heart failure take part in. DMP for single diseases and lone-standing self-management interventions for patients with multimorbidity have shown to be helpful (e.g., [28,29]), which supports the patient-education QI (see also [12]). While a recent systematic review supports the importance of monitoring treatment effects and clinical parameters [30], this is no plea for generalised periodic check-ups without a definite indication.

The proposition of a GP-coordinated care was not supported by the expert panel as this care model is not yet sufficiently embedded within routine care in Germany [31], although §73 SGB V [32] makes way for general practitioner-centred primary care (coordination) since 2003, which is also highlighted in the policy paper of the German College of General Practitioners and Family Physicians from 2012 [33].

Literature-based QI validated by the FGs focus mostly on aspects that address interpersonal communication, holistic treatment approaches and processes that allow patients to make their own choices based on comprehensive information. This aligns our findings with the wide scientific consensus that the treatment of patients with multimorbidity should be informed by a patient-centred approach [12,34–36]. The majority of the quality statements proposed by NICE [37] align with the indicators resulting from our study (e.g., “assessing values, priorities and goals”, “care coordination” and “reviewing medicines and other treatments”). All measurement frameworks seem to have one thing in common: taking shared-decision making into account as central aspect of patient-centred care [38].

An explanation for the lack of support for the QI dealing with screening and assessment issues might be due to the participants’ perspective as individuals and end users of care structures and processes. Qualitative methods are mostly able to elicit patients’ personal experiences with and views on health care (processes) and laypersons are seldom confronted with meta-level issues directed at groups of patients and not individual patients.

Other projects aiming at the development of quality frameworks in multimorbidity predominantly focussed on outcome measurement [39–41]. Scientific evidence on generic health outcome measures to assess quality of care for PM is still lacking. In the light of PM's individual goals and priorities it proves difficult to define outcome indicators suitable for all. Keeping that in mind, our QI set addressing mainly care processes and covering a broad range of care domains is evidence-based and seems to be very adequate for the evaluation of quality of care for PM.

Future research

Primary care patients (≥65 years) and their GPs will be questioned using standardized patient reported outcome measures (related to the identified QI) and other instruments (measuring indicator manifestation) will be used to study validity and applicability of the developed set of QI. The definite set of QI will be determined based on the study results.

Practical implications

Our QI set can be used as a framework for assessing the quality of care in the German health care system. It will facilitate implementation of treatment standards, increase the use of existing guidelines [10,42] and help to reduce over-, under- and misuse of healthcare resources. The QI set will serve as a reference framework for future evaluations of complex interventions and care models for PM.

CONCLUSION

Our study has proven that FGs with patients and their relatives add important aspects in QI development, should be incorporated by default in QI development processes and constitute a reasonable addition to traditional QI development [12,13]. Future challenges lie in the adoption of these quality criteria as practical and valid standardized measures and their implementation in primary care.

Author contributions

MS, DL, JSz: Acquisition of funding for and conception, design and supervision of the study. AB, KG, NP, JSc: moderation of focus groups. AB, KG, CH, NP and JSc: data analysis and interpretation. NP: drafting of the manuscript. AB, KG, CH, DL, JSc, JSz, MS: critical revision of former versions and final approval of the manuscript.

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Data availability statement

The data generated and analyzed during the current study are not publicly available due study’s assurances to participants that the full raw focus group data would not be shared publicly, and that all attempts would be made to maintain confidentiality. We named the people who are responsible for data analysis to the focus group participants in the written consent and they did not agree to the sharing of the full raw data.

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Competing Interests

None declared.

Ethics Approval

Ethics approval was obtained from the Ethics Committee of the Hamburg Medical Association, (10th September 2018, PV5846), from the Clinical Ethics Committee Heidelberg (19th December 2018, S-665/2018), and the Medical Association of Baden-Wuerttemberg (13th November, B-F-2018-096).

Consent to participate

Participants gave written informed consent to participate in the study and for the FGs to be recorded, transcribed and the data being published anonymously.

Consent for publication

Not applicable.

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Quality of care for people with multimorbidity: A focus group study with patients and their relatives

The Patient – Patient-Centered Outcomes Research

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Guideline for Focus Groups with Patients

„Experiences of people with three or more chronic conditions and their relatives with primary care“

1. Entry: introduction round

Before we discuss your experiences, I would like to do a small round of introductions.

1.1 Please introduce yourself briefly one by one. Please state your name, age and your chronic diseases.

2. Experiences

Introductory question: What has changed for you in your primary care compared to the past, since you no longer have only one, but three or more chronic diseases?

2.1 Positive experience with primary care

I would like to ask you to tell us about your positive experiences with primary care.

2.1.1 What experiences have you had so far with your GP where you felt particularly well taken care of? Please think of your experiences as a patient with multiple chronic diseases at the same time.

2.1.2 What expectations do you have for your GP and his team?

2.2 Negative experiences with primary care

2.2.1 What experiences with your family doctor have you had so far where you felt that you were not well taken care of? What happened? Please also give reasons for your negative evaluation.

2.2.2 What would you have wished for in connection with this negative experience?

3. Vision for primary care

3.1 If you pause for a moment and think about the situation of people with multiple chronic diseases in general: Which problems do you think exist in the primary care of people with several chronic diseases?

3.2 Please tell us what good primary care for patients with multiple chronic diseases looks like or should like.

3.3 Imagine if **you** could design primary care for people with three or more chronic diseases yourself. What would ideal primary care look like for someone like you?

4. Conclusion of the discussion

Now we have come to the end of the first part of the discussion. We have talked about many things. Is there anything that we have not yet addressed, but that is still important to you and that you would like to add?

Break

5. Prioritization

During the break we have collected the aspects you find important for the primary care of people with multiple chronic diseases. Now we would like to ask you to evaluate these aspects and to give 1 to 4 points depending on their importance: 4= very important, 3= rather important, 2 = rather not important, 1= not important.

Now we would like you to explain why those aspects which you have given 4 points are so important to you.

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Guideline for Focus Groups with Relatives

„Experiences of people with three or more chronic conditions and their relatives with primary care "

1. Entry: introduction round

Before we talk about your experience, I would like to do a small round of introductions.

1.1 Please introduce yourself briefly one by one. Please state your name, age and the chronic illnesses that affect your relative.

1.2 Please also briefly describe your relationship with your relative, who has multiple chronic conditions, and the extent to which you are involved in their care.

2. Experiences

Introductory question: In your opinion and your experience, what has changed in primary care compared to the past since your relative no longer has not only one but multiple chronic diseases?

2.1 Positive experiences with family doctor care

Now I would like to ask you to tell us about your good experiences with the family medical care of your relative, who is affected by several chronic diseases.

2.1.1 What experiences have you had so far where you would say that the GP was taking particularly good care of your relative?

2.1.2 What expectations/wishes do you have for the medical care of your relative who is affected by multiple chronic diseases?

2.2 Negative experiences with primary care

2.2.1 What experiences with medical care have you had where you would say that you and your relative was not well taken care of? Please also give reasons for your negative evaluation.

2.2.2 What would you have wished for in connection with this negative experience?

3. Vision of optimal primary care

3.1 If you pause for a moment and think about the situation of people with multiple chronic diseases in general: Which problems do you think exist in the primary care of people with several chronic diseases?

3.2 Please tell us what good primary care for patients with multiple chronic diseases and their relatives looks like or should like.

3.3 Imagine if **you** could design primary care for people with three or more chronic diseases yourself. What would ideal primary care look like? What would you wish for as a family member?

4. Conclusion of the discussion

Now we have come to the end of the first part of the discussion. We have talked about many things. Is there anything that we have not yet addressed, but that is still important to you and that you would like to add?

Break

5. Prioritization

During the break we have collected the aspects you find important for the primary care of people with multiple chronic diseases. Now we would like to ask you to evaluate these aspects and to give 1 to 4 points depending on their importance: 4= very important, 3= rather important, 2 = rather not important, 1= not important.

Now we would like you to explain why those aspects you have given 4 points are so important to you.

COREQ

"Quality of care for people with multimorbidity – A focus group study with patients and their relatives"

Topic	Item No.	Guide Questions/Description	Reported on Page No. (Comment)
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	p. 5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	p. 7
Occupation	3	What was their occupation at the time of the study?	p. 7
Gender	4	Was the researcher male or female?	p. 7
Experience and training	5	What experience or training did the researcher have?	p. 7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	p. 5
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Researchers introduced themselves and the study at the beginning of the focus group meetings.
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	p. 7
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	p. 6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p. 4/5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	p. 5
Sample size	12	How many participants were in the study?	p. 8
Non-participation	13	How many people refused to participate or dropped out? Reasons?	p. 8
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	in the department's meeting room
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	Trained research assistant taking notes
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	p. 5/8
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See suppl. files 1+2

Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	No, not applicable
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	p. 5
Field notes	20	Were field notes made during and/or after the interview or focus group?	No, not applicable
Duration	21	What was the duration of the inter views or focus group?	Approx. 120-135 minutes
Data saturation	22	Was data saturation discussed?	No, because theoretical saturation is a concept originally developed within Grounded Theory. Later, it was termed data/thematic saturation for other qualitative methods. While the concept of saturation has helpfully been translated for other qualitative approaches it is not appropriate to impose it on all instances, for example conversation analysis and qualitative content analysis (using purposive, not theoretical sampling).
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	No. We did not return the transcripts to the focus group participants as this does not seem to be the usual procedure in studies using focus groups and qualitative content analysis and would have meant an unduly demand from the patients.
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	p. 6
Description of the coding tree	25	Did authors provide a description of the coding tree?	p. 8-18
Derivation of themes	26	Were themes identified in advance or derived from the data?	p. 6
Software	27	What software, if applicable, was used to manage the data?	p. 7
Participant checking	28	Did participants provide feedback on the findings?	No. In health services research, where the data collection is an one-off exercise, participant checking might be more trouble than it is worth, especially in respect to the expenditure of the participants time. We therefore choose to ensure intersubjective reproducibility and comprehensibility by discussing the results with an interdisciplinary workgroup for qualitative methods.
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	p. 8-18 and table 1
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes, we think that data and findings presented are consistent, but also think that it is the readers'/reviewers' right/duty to judge about that.
Clarity of major themes	31	Were major themes clearly presented in the findings?	p. 8-18
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	p. 8-18

BMJ Open

Quality of care for people with multimorbidity: A focus group study with patients and their relatives

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Quality of care for people with multimorbidity: A focus group study with patients and their relatives

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ABSTRACT

Background

Prevalence of people with multimorbidity rises. Multimorbidity constitutes a challenge to the health care system, and treatment of patients with multimorbidity is prone to high quality variations. Currently, no set of quality indicators (QI) exists to assess quality of care, let alone incorporating the patient perspective. We therefore aim to identify aspects of quality of care relevant from the patients' perspective and match them to a literature-based set of QI.

Methods

We conducted eight focus groups with patients with multimorbidity and three focus groups with patients' relatives using a semi-structured guide. Data was analysed using Kuckartz's qualitative content analysis. We derived deductive categories from the literature, added inductive categories (new quality aspects) and translated them into QI.

Results

We created four new QI based on the quality aspects relevant to patients(' relatives). Two QI (patient education/self-management, regular updates of medication plans) were consented by an expert panel, while two others were not (periodic check-ups, general practitioner coordinated care). Half of the literature-based QI, for example assessment of biopsychosocial support needs, were supported by participants' accounts, while more technical domains regarding assessment and treatment regimens were not addressed in the focus groups.

Conclusion

We show that focus groups with patients and relatives add relevant aspects in QI development, should be incorporated by default in QI development processes and constitute a reasonable addition

to traditional QI development. Our QI set constitutes a framework for assessing the quality of care in the German health care system. It will facilitate implementation of treatment standards and increase the use of existing guidelines, hereby helping to reduce overuse, underuse, and misuse in the treatment of patients with multimorbidity.

German Clinical Trials Register: DRKS00015718, registration date: 15th of October 2018

Strengths and limitations of this study

- affected patients and their relatives (who often function as informal caregiver) were interviewed in the focus groups
- focus group participants from two differently structured regions in Germany representing a wide spectrum of combinations of different diseases were queried
- focus groups with patients and their relatives (asking about positive and negative experiences with care) seem to be an effective tool to identify quality aspects relevant for QI development

INTRODUCTION

Our society is aging and higher life expectancy is associated with higher rates of chronic diseases. Care for patients with multimorbidity is likely to evolve into one of our most prominent challenges in the future [1,2]. Multimorbidity is strongly linked to functional limitations, lower quality of life and increase in health care utilization, costs and higher mortality [3,4]. Care for patients with multimorbidity is very complex [5] and therefore prone to deficits in quality and major (unintended) interindividual differences regarding the impact of illness and carer performance [6–9]. Multimorbidity creates many challenges to general practitioners (GPs) and affected patients alike, e.g. (too) short consultation times, polypharmacy, increased health care utilization, high treatment burden and self-management requirements as well as psychological distress [10,11]. Several decades of research and discussion have provided us with suggestions for management approaches in primary care to better address the needs of this patient group, inter alia, the Chronic Care Model [12,13] and the meta-algorithm [14] for treating patients with multimorbidity.

Generic standards for high quality of care are hard to define due to the infinite number of possible (combinations of) medical problems in patients with multimorbidity. Evidence-based standards relevant to patients with multimorbidity are urgently needed, because single disease clinical guidelines are for several reasons often inadequate for this patient population [10]. As long as the current state of health care cannot be mapped systematically, for example by using a set of quality indicators (QI) specific for multimorbidity, it remains impossible to compare the effects of interventions and health care models to optimize quality or to identify sectors, regions or health care providers needing improvement.

In Germany, the first point of contact in the health care system for people who fall ill is usually a general practitioner. GPs are usually licensed to provide care on the basis of contracts with the statutory health insurance (SHI) and are member of the corresponding association of SHI doctors. The statutory health insurance covers about 90% of Germany's residents and is complemented by a private health insurance system. German GPs have usually completed five years of further training to be allowed to call themselves specialists in general practice/primary care. Patients are free to consult any GP unless they choose to enrol themselves in a GP contract ("Hausarztzentrierte Versorgung"). The contractually defined GP-coordinated care further strengthens the role of the GPs as guides and coordinators for the health care of their patients [15]. GPs refer patients to outpatient specialists or hospitals when further or specialized care is needed. There are more than 100 different types of patient record management software [16] and usually the patient records of different doctors are not linked, which means that their communication and coordination often relies on (referral/discharge) letters and patients' reports.

Taking the patients' perspective into consideration is even more relevant when dealing with patients with multimorbidity. Every decision made concerning risks and benefits of treatments and interventions has to be weighed against individual impairments, comorbidities and gain in subjective quality of life [14]. Prioritization must take the whole range of biopsychosocial complexities into account and follow principles of patient-centred clinical management and decision making. Views on high quality health care often differ between patients and their health care providers [17,18]. For example, quality of care seems to be higher when process or intermediate outcome indicators are measured and lower when patient-reported experiences of care are reviewed [18]. Therefore patients can [19] and must be involved in guideline and QI development [20–23]. Studies show that this is not often the case [21] even though approaches to patient involvement in QI development, e.g. focus groups, exist and are considered to be of high value [20].

The MULTIqual project aims at the development of a quality indicator set which can be used to evaluate the current state of health care provided for patients with multimorbidity and to promote the implementation of treatment standards for future care. We conducted focus groups with patients with multimorbidity and their relatives to validate and amend a literature- and expert consensus-based set of QI by qualitatively surveying their views on health care quality.

METHODS

The MULTIqual project is a multi-centre mixed-methods project comprising a systematic literature review, focus groups, a two-stage expert consensus process and a quantitative survey with patients with multimorbidity and general practitioners. Following the COREQ [24] this paper presents the results of focus groups with patients with multimorbidity and their relatives conducted in Hamburg and Heidelberg and of the expert consensus on the qualitatively derived QIs. Further details on the systematic literature review, expert panel, consensus process and quality indicator development process that are not directly relevant for the work presented here will be described extensively elsewhere (manuscript in preparation).

Participant selection and recruitment

We randomly selected the GPs from the register of SHI-accredited doctors of the city districts or within a radius of 25 km around the two study centers respectively. We invited the selected GPs to participate in our study and informed them in detail about the project if they were interested. Participating GPs were asked to recruit patients aged 65 and above with three or more chronic conditions that attended the practice at least once in the last three months. Patients with multimorbidity willing to participate were asked to invite close relatives to take part in the study as well. Exclusion criteria were insufficient knowledge of the German language and inability to give informed consent. Patients received an invitation containing study information, a response sheet and a reply envelope. Participants received an allowance of 30€ plus a reimbursement of travel expenses. Participants gave written informed consent for the focus groups to be recorded, transcribed and the data being published anonymously.

Focus group guide

Guide development was based on the literature review (e.g., [25]) and the research questions outlined above. As lay persons mostly relate to implicit experiential knowledge when defining quality criteria (e.g., [26,27]), we chose to question our focus group participants about their own positive and negative experiences with primary health care, changes in their health care needs and experiences due to multimorbidity and their vision of ideal primary care for people like them (see suppl. file 1 for 'patients' focus group guide'). With patients' relatives, the same topics were discussed in respect to the associated patient with multimorbidity (see suppl. file 2 for 'relatives' focus group guide').

Data collection

Either JS, CH, AB or KG had spoken to the participants on the phone, but had no other relationship with them. In 12/2018 and 01/2019 we conducted eight focus groups with patients with multimorbidity (city A =3, city B= 5) and three focus groups with patients' relatives (A=1, B=2) using the semi-structured guides described above. Two moderators facilitated the focus groups (NJP, JS, KG, AB, CH and TKl respectively) which lasted about two hours. Discussions were digitally recorded and transcribed verbatim by a trained research assistant following designated transcription rules. Accuracy of the transcripts was checked by the respective moderators. In order to protect the focus groups participants' identity, names and other identifying details were changed during transcription.

Data analysis

Data were analysed using the qualitative content analysis approach described by Kuckartz [28], following a realistic paradigm [29]. Coders (NJP, CH and JS) read all transcripts to familiarize with the data. Transcripts were broken down into fragments adopting different sizes ranging from part of a sentence to one or more paragraphs in relation to the segment length needed to understand the content and context of the relevant accounts. We created deductive codes representing the aspects of quality described in the literature-based QI set and selected by the expert panel and inductive codes when new aspects of quality emerged from the data (see below). We then subjected all transcripts to a second round of coding by a different coder. Coding was carried out with constant discussions between the three coders about the coded text passages and assigned codes. To ensure intersubjective reproducibility and comprehensibility [30], the results were presented to and discussed with the interdisciplinary workgroup 'qualitative methods' and the co-authors DL (postdoctorate, MD) and MS (professor, MD). Data was managed using MAXQDA 11 (Verbi GmbH).

Identification of additional patient relevant quality aspects and expert rating of deduced QI

We aimed to supplement the preliminary QI set extracted from a systematic literature review by QI based on patient-relevant quality aspects derived from the focus group data. A multidisciplinary research team (NJP, CH, KG, AB and JS) allocated subjectively important quality aspects from patients' and their relatives' views to the preliminary set of QI based on the literature review and identified important additional quality aspects where needed. Afterwards the research team transformed the additionally identified quality aspects into QI (including description, numerator, denominator, exclusion criteria etc.). These QI were presented by NP to an expert panel during an in-person meeting. The expert panel consisted of representatives of primary care, nursing, practice management, quality research methodology, social work, physical therapy, geriatrics, clinical pharmacology, social medicine and patient representatives. The in-person meeting took place on 1st February 2019. During the meeting NJP presented the focus group-material-based new QI to the expert panel. After a rating of relevance, strength of evidence and their potential for undesirable effects, the expert panel voted for keeping or rejecting the QI deduced from the focus group material via nominal group technique.

Patient and public involvement statement

Patients were involved in the recruitment of focus group participants (viz. their relatives). Patient representatives and representatives of relevant fields (see above) were involved in the rating and selection of QI. Apart from that there was no patient or public involvement in the study.

Researcher characteristics

Researchers' characteristics, beliefs and assumption influence qualitative research and data interpretation. NJP (♀): post-doc psychologist, experienced qualitative researcher (patient involvement in QI development, health care research focusing on general practice). JS (♀): psychologist/junior scientist. CH (♀): medical student. AB (♀): junior scientist, M.A. Health Information Management. DL (♀), KG (♀), JSz (♂), MS (♂): medical professionals, experienced post-doc researchers in the field of general practice and QI development.

RESULTS

Participants characteristics

We included 29 female and 18 male patients aged 65-84 years as well as three female and six male relatives (five spouses/four children) aged 49-78 years in five patient groups, and three relatives groups, respectively. Nine registered volunteers did not take part, with n = 3 due to acute health problems and n = 6 due to organizational difficulties.

Focus group-based additional quality aspects included into the QI set after the expert panel rating

Two focus-group based quality aspects were finally supported by the expert panel and included in the QI set.

Patient education / self-management

Patients consider it very helpful to be informed about their diseases and possible (self-) treatment and management strategies (for example, nutrition counselling). Daily disease management can be supported by specific information on self-management strategies, training in disease-related competencies (for example, measuring the INR value), addressing coping strategies and provision of knowledge for the patient.

> *"I took part in a course in [city] and have been monitoring my 'Quick' [prothrombin time] myself for over 20 years and I have a book and also keep a record. And I always took it with me to the hospitals and the doctors were amazed that they could see exactly how I did it and how I tested my 'Quick'. […] And I always write it down and then I dose the medication myself. No, I am still grateful to the doctor for giving me the tip that I can do the course how to measure my 'Quick' on my own […]."*
>
> *(city B, patient focus group A, paragraph 162-166)*

Regular updates of medication plan

Patients report to have been provided with medication plans and consider it very important for them to be up-to-date especially when taking a high number of different medications or when medication is prescribed by specialists. Some patients always have copies of their medication plan at hand in case of an emergency and it would be considered helpful if this plan was accessible electronically on the health insurance card.

> *"This is also from the GP, right? It's a medication plan. So you know when to take it and so on. One should know that. But also that you can show it, if someone asks: 'What are you taking?' Oh god, yes, what am I taking? What's it called again? It just changed again, hasn't it? Well, I know it, but it's also good for the other doctors if they have something printed and to be able to see exactly what she needs, what she takes, how often and when […]. So, it is very pleasant when GPs do something like that. Gives you a certain amount of security."*
>
> *(city A, patient focus group B, paragraph 251-253)*

Focus group-based additional quality aspects not included into the QI set after the expert panel rating

Two other indicators were not supported by the expert panel and not included in the final QI set.

Regular check-ups

Patients with chronic diseases see a need for regular check-ups as it would allow for early detection of health deterioration and they know these procedures from the disease management programmes, e.g. for diabetes or COPD. They value the regular contact with the GP at fixed appointments.

> *"[...] if you take these medications regularly and then say: "We'll have a general check-up once every two years" – I think that's not enough. I think it should be every year. The status should be checked once in a while, if I'm taking these pills regularly."*
>
> *(city A, patient focus group C, paragraph 97)*

General practitioner coordinated care

Patients appreciate the GPs to coordinate their care which involves for example writing referral letters for specialist visits (and the GP receiving medical reports), having a network of specialists at hand, planning preventive measures and keeping track of medications and their interactions and side effects. Patients who describe their relationship with their GP as trusting, want all information on their health care to converge at their GPs' practice.

> *"[...] when the diagnoses are made and the GPs know what's going on, then they should actually act as a control center and have the possibility to coordinate everything."*
>
> *(city A, patient focus group A, paragraph 264)*

> *"That's a given in our practice. He always wants to give you referrals because he wants to have doctor's letters. Otherwise he says he doesn't have an overview. And I think that's very, very good."*
>
> *(city B, relatives' focus group A, paragraph 66)*

Literature-based quality aspects supported by focus groups

Table 1 gives an overview of quality aspects identified in the literature review and supported by both focus groups and expert consensus and shows supporting quotes from the focus groups. Descriptions of categories shown table 1 follow below.

Table 1: Quality aspects identified in the literature and supported by focus groups and expert panel ratings

Patient-related factors	Assessment of biopsychosocial support needs	“So for me, I would like to see myself not only as a body, or only as organs, but as a complex human being. That’s very important for me, […] this union of body, mind and soul." (*city B,* patient focus group A, paragraph 70) “This is certainly an aspect that the doctors should [...] actually take a closer look at again: What is the situation at home? Does the person need support? Do we have to organize something?” (*city B,* relatives' focus group A, paragraph 91)
	Involving partners, family and caregivers	“Perhaps this could be discussed in a phone call with relatives, so that I am informed about the current situation, what is pending or how the medication maybe, yes, what I have to pay attention to as a caring relative and, as I said, if this is okay for my mother, as I know that she is not informed at all.” (*city B,* relatives' focus group A, paragraph 174)
Physician-patient-interaction	Shared decision-making and mutual agreement on treatment goals	“A doctor's sole decision: (.) "Do this or that" - if the patient doesn't agree, it is pointless (...). He won't do it anyway. (..) And that's why I think that those issues really need to be discussed together. And determined together what is possible for the patient. Not everything is possible." (city A, patient focus group A, paragraph 468) “[...] we discussed it [...] at eye level in a VERY thorough conversation, so that we decided on the therapy regimen together, which I follow, and use take control of the disease." (city A, patient focus group A, paragraph 21)

	Information about medication and potential benefits and harms of treatment	“It's important to me [...] that I get information in an […] understandable way about what is going on with me and how this could be treated.” (city A, relatives' focus group A, paragraph 357) “And then that in some cases he may explain the disease. Not the disease, but the measures, that's the way I wanted to put it. But then we come back to the time factor again. But in some cases, as I said, it is done this way. So that you get a little more time and get information about what is actually going on and what you can do about it. Or against it.” (*city B,* relatives' focus group B, paragraph 98) “But it’s just that when I get pills and it says this and that and you don’t even know what it’s for. […]” (*city B,* patient focus group C, paragraph 43)
	Medication review and documentation of adverse drug reactions	“Especially in the case of multiple chronic diseases, I find it extremely important that the general practitioner explains to me that the drugs are compatible, that there is no interaction or that it is possible that they will cancel each other out or even worsen the condition, as in the case of my mother […]”(*city B,* relatives' focus group A, paragraph 69) “I also consider close monitoring of drug effects and side effects important. Because there are side effects that one does not even register, which develop so insidiously. So it's a good thing that experts with their backgrounds check for possible side effects and say: “Watch this, something is happening to you, that doesn't fit in or it's a side effect”.

		Because I only read the package insert when I really have something and suspect a side effect. I do not read them in advance. Because then you don't take the drug." (city A, relatives' focus group A, paragraph 357)
	Written treatment plan	"I packed a little something from my management. I don't know if you know anything like that, here is a blood sugar diary for people on insulin. This is from the diabetes clinic. It contains all my data, every record, both blood sugar levels and blood pressure and then the insulin dose. And I also check my weight and write it down here, so I always keep everything together. And I take this to my general practitioner as well as to the other doctors, for example to the eye specialist. And I think that's good." (city A, patient focus group A, paragraph 167-168)
Context and Organizational Structures	Comprehensive care documentation	"I think [...] to keep an overview of the attending specialists is actually very important. Because [...] when I go to the eye specialist or ear, nose and throat specialist, and the GP doesn't even know this, and usually doesn't get a medical report from them either, then he is actually missing out […] on important information. I could have glaucoma, or whatever. And he doesn't even know about it and he doesn't even know what kind of medication you might have to take. […]" (city A, patient focus group A, paragraph 466)
	Training programmes addressing	"Whereby I have to say with my GP's joint practice, you can't complain. So there are two [employees], I think, they are still trained nurses. That's how long they've been at it. They are REALLY competent. And I'd say they already

	management of patients with multimorbidity	have a certain diagnostic instinct. They can tell when someone comes in with swollen eyes, whether it's just a flu-like infection or a real flu, that he should perhaps be isolated." (city A, relatives' focus group A, paragraph 108) "Well, of course we have the problem that we have more and more elderly people who are sick, and have multiple diseases. And we have fewer and fewer GPs. So, I think it would be a very good care model if we had, for example, registered physicians who specialize in geriatrics. I think it would be a good care model if we had general medical training, with additional specialization, for example in mental health. I would prefer geriatrics and that these doctors with such training, who also have many, many or mostly older patients, are given more time. That perhaps, there are also these reference numbers, what they can charge. Because, we have to get there, because there are more and more elderly people, that they would get the possibility, the aspect of time and if it is only five minutes. Five minutes is a lot per patient. But that is of course an idle wish [...]" (*city B,* patient focus group A, paragraph 85)

Assessment of biopsychosocial support needs

Patients expressed a need for the GP to have a holistic view on the patient's health problems and needs. They underlined the importance of not only seeing and treating physical symptoms, but also the overall picture of medical and psychosocial aspects of the patient's situation. They consider it important for the GP to have at least basic information on the patient's background and personal history. Sometimes house calls can be necessary for a realistic judgement on biopsychosocial support needs for example for elderly people with beginning dementia.

Involving partners, family and caregivers

Relatives of people with multimorbidity often appreciate the GPs' willingness to communicate with them and support them in the process of giving care. Support and advice are often desperately needed by informal caregivers of persons with multimorbidity, especially if dementia is an issue. GP's awareness of informal caregivers' problems and concerns is important and could for example be addressed by offering consultation hours for relatives and other informal caregivers.

Shared decision-making and mutual agreement on treatment goals

Shared decision-making to find a customized treatment approach for individual patients is highly appreciated by the focus group participants. Communicating, informing and deciding on treatment regimens and goals on a par with the patient are seen as essential for increasing adherence and patient satisfaction. Patients value the freedom to set their own priorities and make decisions based on their values and preferences concerning their health and health care behaviour. They appreciate their GPs supporting them in this approach and the autonomy this respect gives them.

Information about medication and potential benefits and harms of treatment

Our focus group participants did not differentiate clearly between information and advice on their diagnosis, disease or condition and risks, medications (for example indication, dosage and interactions) or non-pharmacological treatments and their benefits and potential side effects. They emphasize the importance of detailed and comprehensible information on all these aspects. Either way, some stated not to be interested in very detailed descriptions of potential risks and side effects. The amount of information given must be tailored to the patient's needs even though these consultations might need more time than usually budgeted.

Medication review and documentation of adverse drug reactions

Medication reviews are highly acclaimed by the focus group participants. Patients and their relatives wish for the GP to check for interactions regularly especially with medication prescribed by others and over-the-counter (OTC) drugs. They expressed criticism of the high numbers of prescribed drugs and low engagement of health professionals to actively inquire about drug-related problems and to search for highly tolerable medications. Patients focus less on the thorough documentation of adverse drugs reactions than on their monitoring and handling. They wish for the GP to detect signs of adverse effects and monitor them for example through regular follow-ups.

Written treatment plan

Focus group participants' recognize the value of written treatment schedules that include overviews on scheduled health care appointments plus instructions, e.g., whether they have to appear with an empty stomach for bloodwork. They emphasized the advantages of automated recalls systems. Another focus was on recorded treatment protocols, e.g. keeping a blood pressure journal or a diabetes log book containing measured values and other relevant parameters. Patients proposed using digital solutions for facilitating care coordination between different providers.

Comprehensive care documentation

The vast majority of the focus group participants consider comprehensive care documentation as a vital part of high quality care, emphasizing importance of the exchange of information on diagnostic testing or examination results and prescribed medication, giving the GP the opportunity to coordinate care and consult the specialist about the patient’s treatments. Patients report that the responsibility for this exchange is often in the patients’ hand, being the ones to take care of specialists’ letters being issued to the GP. Under the premise of data security, patients would support a digital exchange of doctor’s letters, but sometimes doubt the ‘digital competencies’ especially of the older generation of physicians.

Training programmes addressing management of patients with multimorbidity

Patients put emphasis on the competencies of the practice team. For medical assistants this means for example being experienced in taking blood samples or administering vaccinations or injectable medications. Another aspect is the ability to triage patients according to the severity and urgency of their treatment needs. GPs should engage in continuous medical education, be up-to-date on actual research results and technological advances. Participants valued additional training in the field of geriatrics or psychology and proposed regular supervision and peer consultation for complex problems in multimorbid patients.

Literature-based quality aspects not supported by focus groups

Table 2 gives an overview of quality aspects identified in the literature review and supported by the expert panel but not accounted for in focus groups. As this paper focuses on the focus group result, these quality aspects are described extensively elsewhere (manuscript in preparation).

Table 2: Literature-based quality aspects not supported by focus groups

Patient-related factors	Screening for depression
	Proactive pain assessment
	Monitoring of pain management
	Addressing financial support needs
	Quality of life assessment

	Assessment of symptom burden
	Establishing patient preferences
Physician-patient-interaction	Identification of patients with multimorbidity
	Assessment of treatment burden
	Monitoring adherence to treatment
Context and Organizational Structures	Assigning responsibility for coordination of care

DISCUSSION

Main results

By asking patients with multimorbidity and their relatives in focus groups about their experiences with primary health care we were able to identify important quality aspects from their point of view and derived four new patient-relevant QI to date not represented in guidelines or the literature on quality of care in multimorbidity. Out of these, two QI concerning regular updates of written medication plans and patient education and fostering self-management were supported by the expert panel. On the other hand, regular check-ups and GP-coordinated care were not supported by the expert panel. Half of the literature-based QI, for example assessment of biopsychosocial support needs, establishing patient preferences and shared decision-making, were supported by participants' accounts, while more technical domains regarding assessment and treatment regimens were not covered in the focus groups.

Strength and limitations

To obtain a comprehensive picture of aspects of quality of care from the affected persons' point of view we asked not only patients with multimorbidity, but also their relatives (often informal caregivers) in separate groups. Focus group participants were recruited in two very differently structured regions of northern and southern Germany and represent a wide spectrum of combinations of different diseases. We therefore assume that our results might be cautiously generalizable to patients with multimorbidity in primary care all over Germany. However, the experiences reported by patients with multimorbidity and their relatives in the focus groups may to some extent be specific to the German healthcare system. In other countries, such as the UK, for example, medication reviews and the provision of medication information are the responsibility of pharmacists. Our results should not be transferred to other countries without cautious reflection, as the organisation of health care systems and the implementation of (primary) care differ between Germany and other countries.

Reflecting and evaluating own experiences is dependent on representation of different perspectives, lived experiences and group interaction, and must be fragmentary, as participants were lay persons regarding health care (quality). Therefore, it did not seem feasible to ask the participants to propose QI. Instead, we focussed on positive and negative experiences with primary care and derived patient-relevant QI indirectly. As many accounts can be matched to QI derived from the literature and half of the newly developed QI were supported by expert consensus this methodology seems to be plausible and practicable.

Although the questions focussed on experiences regarding the related patients with multimorbidity, the results from focus groups with relatives show that for some participants it was difficult to focus on their role as (caregiving) relative. Many participants referred to their own health care experiences being affected by multiple conditions themselves, which reflects the spectrum of issues and challenges in the field as the prevalence of multimorbidity increases in older age [31].

Discussion of results and comparison with existing literature

The complexities of managing multimorbidity are widely known [10] and there is a growing amount of literature on interventions for improving outcomes in patients with multimorbidity [11,32]. Different approaches to tackle the challenges of caring for patients with multimorbidity were discussed, from the Chronic Care Model [13], a systematic collection and review of interventions [32] and quality standards [33] to a German meta-algorithm [14], but a quality indicator set involving the perspective of affected patients and their (potential) informal caregivers is still missing.

Since 2016, patients enrolled in statutory health insurance in Germany have a right to be provided with a recorded medication plan if they are prescribed at least three different long-term medications, which is very much appreciated by persons with multimorbidity in our study and elsewhere [34]. If patients consent, these data can be saved to the electronic health card or record to allow for a standardized digital exchange of this information of these data between providers [35,36]. Despite preferring a written medication plan and stating the problem of insufficient communication between prescribing physicians, participants of our focus groups judged this incorporation ambivalently as they saw problems concerning data safety and confidentiality [37] as well as (older) GPs digital literacy.

Patients' with multimorbidity wish for patient education, fostering of self-management and periodic check-ups might arise from their experiences with patient education and regular control of, e.g., blood values, respiratory function and blood pressure during the structured disease management programmes (DMP, e.g., [38]) that many patients with diabetes, COPD or heart failure take part in. DMP for single diseases and lone-standing self-management interventions for patients with multimorbidity have shown to be helpful (e.g., [39,40]), which supports the patient-education QI (see also [19]). While a recent systematic review supports the importance of monitoring treatment effects and clinical parameters [11], this is no plea for generalised periodic check-ups without a definite indication.

The proposition of a GP-coordinated care was not supported by the expert panel as this care model is not yet sufficiently embedded within routine care in Germany [41], although §73 SGB V [42] makes way for general practitioner-centred primary care (coordination) since 2003, which is also highlighted in the policy paper of the German College of General Practitioners and Family Physicians from 2012 [43].

Literature-based QI validated by the focus group focus mostly on aspects that address interpersonal communication, holistic treatment approaches and processes that allow patients to make their own choices based on comprehensive information. This aligns our findings with the wide scientific consensus that the treatment of patients with multimorbidity should be informed by a patient-centred approach [19,44–46]. The majority of the quality statements proposed by National Institute for Health and Care Excellence (NICE [33]) align with the indicators resulting from our study (e.g., “assessing values, priorities and goals”, “care coordination” and “reviewing medicines and other treatments”). All measurement frameworks seem to have one thing in common: taking shared-decision making into account as central aspect of patient-centred care [47].

An explanation for the lack of support for the QI dealing with screening and assessment issues in the focus groups might be due to the participants’ perspective as individuals and end users of care structures and processes. Qualitative methods are mostly able to elicit patients’ personal experiences with and views on health care (processes) and laypersons are seldom confronted with meta-level issues directed at groups of patients and not individual patients.

Other projects aiming at the development of quality frameworks in multimorbidity predominantly focussed on outcome measurement [48–50]. Scientific evidence on generic health outcome measures to assess quality of care for patients with multimorbidity is still lacking. In the light of patients’ with multimorbidity individual goals and priorities it proves difficult to define outcome indicators suitable for all. Keeping that in mind, our QI set addressing mainly care processes and covering a broad range of care domains is evidence-based and seems to be very adequate for the evaluation of quality of care for patients with multimorbidity.

Future research

Primary care patients (≥65 years) and their GPs will be questioned using standardized patient reported outcome measures (related to the identified QI) and other instruments (measuring behaviour described in the identified QI) to study validity and applicability of the developed set of QI. The definite set of QI will be determined based on the study results.

Practical implications

The QI set finally developed in the MULTIqual-study can be used as a framework for assessing the quality of care in the German health care system. It will facilitate implementation of treatment standards, increase the use of existing guidelines [14,51] and help to reduce over-, under- and misuse of healthcare resources. The QI set will serve as a reference framework for future evaluations of complex interventions and care models for patients with multimorbidity.

CONCLUSION

Our study has demonstrated that focus groups with patients and their relatives add important aspects in QI development, should be incorporated by default in QI development processes and constitute a reasonable addition to traditional QI development [19,20]. Future challenges lie in the adoption of these quality criteria as practical and valid standardized measures and their implementation in primary care.

Author contributions

MS, DL, JSz: Acquisition of funding for and conception, design and supervision of the study. AB, KG, NP, JSc: moderation of focus groups. AB, KG, CH, NP and JSc: data analysis and interpretation. NP: drafting of the manuscript. AB, KG, CH, DL, JSc, JSz, MS: critical revision of former versions and final approval of the manuscript.

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Data availability statement

The data generated and analyzed during the current study are not publicly available due study's assurances to participants that the full raw focus group data would not be shared publicly, and that all attempts would be made to maintain confidentiality. We named the people who are responsible for data analysis to the focus group participants in the written consent and they did not agree to the sharing of the full raw data.

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Competing Interests

None declared.

Ethics Approval

Ethics approval was obtained from the Ethics Committee of the Hamburg Medical Association, (10th September 2018, PV5846), from the Clinical Ethics Committee Heidelberg (19th December 2018, S-665/2018), and the Medical Association of Baden-Wuerttemberg (13th November, B-F-2018-096).

Consent to participate

Participants gave written informed consent to participate in the study and for the focus groups to be recorded, transcribed and the data being published anonymously.

Consent for publication

Not applicable.

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Guideline for Focus Groups with Patients

„Experiences of people with three or more chronic conditions and their relatives with primary care“

1. Entry: introduction round

Before we discuss your experiences, I would like to do a small round of introductions.

1.1 Please introduce yourself briefly one by one. Please state your name, age and your chronic diseases.

2. Experiences

Introductory question: What has changed for you in your primary care compared to the past, since you no longer have only one, but three or more chronic diseases?

2.1 Positive experience with primary care

I would like to ask you to tell us about your positive experiences with primary care.

2.1.1 What experiences have you had so far with your GP where you felt particularly well taken care of? Please think of your experiences as a patient with multiple chronic diseases at the same time.

2.1.2 What expectations do you have for your GP and his team?

2.2 Negative experiences with primary care

2.2.1 What experiences with your family doctor have you had so far where you felt that you were not well taken care of? What happened? Please also give reasons for your negative evaluation.

2.2.2 What would you have wished for in connection with this negative experience?

3. Vision for primary care

3.1 If you pause for a moment and think about the situation of people with multiple chronic diseases in general: Which problems do you think exist in the primary care of people with several chronic diseases?

3.2 Please tell us what good primary care for patients with multiple chronic diseases looks like or should like.

3.3 Imagine if **you** could design primary care for people with three or more chronic diseases yourself. What would ideal primary care look like for someone like you?

4. Conclusion of the discussion

Now we have come to the end of the first part of the discussion. We have talked about many things. Is there anything that we have not yet addressed, but that is still important to you and that you would like to add?

Break

5. Prioritization

During the break we have collected the aspects you find important for the primary care of people with multiple chronic diseases. Now we would like to ask you to evaluate these aspects and to give 1 to 4 points depending on their importance: 4= very important, 3= rather important, 2 = rather not important, 1= not important.

Now we would like you to explain why those aspects which you have given 4 points are so important to you.

Guideline for Focus Groups with Relatives

„Experiences of people with three or more chronic conditions and their relatives with primary care “

1. Entry: introduction round

Before we talk about your experience, I would like to do a small round of introductions.

1.1 Please introduce yourself briefly one by one. Please state your name, age and the chronic illnesses that affect your relative.

1.2 Please also briefly describe your relationship with your relative, who has multiple chronic conditions, and the extent to which you are involved in their care.

2. Experiences

Introductory question: In your opinion and your experience, what has changed in primary care compared to the past since your relative no longer has not only one but multiple chronic diseases?

2.1 Positive experiences with family doctor care

Now I would like to ask you to tell us about your good experiences with the family medical care of your relative, who is affected by several chronic diseases.

2.1.1 What experiences have you had so far where you would say that the GP was taking particularly good care of your relative?

2.1.2 What expectations/wishes do you have for the medical care of your relative who is affected by multiple chronic diseases?

2.2 Negative experiences with primary care

2.2.1 What experiences with medical care have you had where you would say that you and your relative was not well taken care of? Please also give reasons for your negative evaluation.

2.2.2 What would you have wished for in connection with this negative experience?

3. Vision of optimal primary care

3.1 If you pause for a moment and think about the situation of people with multiple chronic diseases in general: Which problems do you think exist in the primary care of people with several chronic diseases?

3.2 Please tell us what good primary care for patients with multiple chronic diseases and their relatives looks like or should like.

3.3 Imagine if **you** could design primary care for people with three or more chronic diseases yourself. What would ideal primary care look like? What would you wish for as a family member?

4. Conclusion of the discussion

Now we have come to the end of the first part of the discussion. We have talked about many things. Is there anything that we have not yet addressed, but that is still important to you and that you would like to add?

Break

5. Prioritization

During the break we have collected the aspects you find important for the primary care of people with multiple chronic diseases. Now we would like to ask you to evaluate these aspects and to give 1 to 4 points depending on their importance: 4= very important, 3= rather important, 2 = rather not important, 1= not important.

Now we would like you to explain why those aspects you have given 4 points are so important to you.

COREQ

“Quality of care for people with multimorbidity – A focus group study with patients and their relatives”

Topic	**Item No.**	**Guide Questions/Description**	**Reported on Page No. (Comment)**
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	p. 7
Credentials	2	What were the researcher’s credentials? E.g. PhD, MD	p. 8
Occupation	3	What was their occupation at the time of the study?	p. 8
Gender	4	Was the researcher male or female?	p. 8
Experience and training	5	What experience or training did the researcher have?	p. 8
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	p. 6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Researchers introduced themselves and the study at the beginning of the focus group meetings.
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	p. 8
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	p. 7
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p. 6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	p. 6
Sample size	12	How many participants were in the study?	p. 9
Non-participation	13	How many people refused to participate or dropped out? Reasons?	p. 9
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	in the department’s meeting room
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	Trained research assistant taking notes
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	p. 6/9
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See suppl. files 1+2

Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	No, not applicable
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	p. 7
Field notes	20	Were field notes made during and/or after the interview or focus group?	No, not applicable
Duration	21	What was the duration of the inter views or focus group?	Approx. 120-135 minutes
Data saturation	22	Was data saturation discussed?	No, because theoretical saturation is a concept originally developed within Grounded Theory. Later, it was termed data/thematic saturation for other qualitative methods. While the concept of saturation has helpfully been translated for other qualitative approaches it is not appropriate to impose it on all instances, for example conversation analysis and qualitative content analysis (using purposive, not theoretical sampling).
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	No. We did not return the transcripts to the focus group participants as this does not seem to be the usual procedure in studies using focus groups and qualitative content analysis and would have meant an unduly demand from the patients.
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	p. 7
Description of the coding tree	25	Did authors provide a description of the coding tree?	p. 9-19
Derivation of themes	26	Were themes identified in advance or derived from the data?	p. 7
Software	27	What software, if applicable, was used to manage the data?	p. 7
Participant checking	28	Did participants provide feedback on the findings?	No. In health services research, where the data collection is an one-off exercise, participant checking might be more trouble than it is worth, especially in respect to the expenditure of the participants time. We therefore choose to ensure intersubjective reproducibility and comprehensibility by discussing the results with an interdisciplinary workgroup for qualitative methods.
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	p. 9-19 and table 1
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes, we think that data and findings presented are consistent, but also think that it is the readers'/reviewers' right/duty to judge about that.
Clarity of major themes	31	Were major themes clearly presented in the findings?	p. 9-19
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	p. 9-19

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Quality of care for people with multimorbidity: A focus group study with patients and their relatives

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Quality of care for people with multimorbidity: A focus group study with patients and their relatives

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ABSTRACT

Background

Prevalence of people with multimorbidity rises. Multimorbidity constitutes a challenge to the health care system, and treatment of patients with multimorbidity is prone to high quality variations. Currently, no set of quality indicators (QI) exists to assess quality of care, let alone incorporating the patient perspective. We therefore aim to identify aspects of quality of care relevant from the patients' perspective and match them to a literature-based set of QI.

Methods

We conducted eight focus groups with patients with multimorbidity and three focus groups with patients' relatives using a semi-structured guide. Data was analysed using Kuckartz's qualitative content analysis. We derived deductive categories from the literature, added inductive categories (new quality aspects) and translated them into QI.

Results

We created four new QI based on the quality aspects relevant to patients(' relatives). Two QI (patient education/self-management, regular updates of medication plans) were consented by an expert panel, while two others were not (periodic check-ups, general practitioner coordinated care). Half of the literature-based QI, for example assessment of biopsychosocial support needs, were supported by participants' accounts, while more technical domains regarding assessment and treatment regimens were not addressed in the focus groups.

Conclusion

We show that focus groups with patients and relatives add relevant aspects in QI development, should be incorporated by default in QI development processes and constitute a reasonable addition

to traditional QI development. Our QI set constitutes a framework for assessing the quality of care in the German health care system. It will facilitate implementation of treatment standards and increase the use of existing guidelines, hereby helping to reduce overuse, underuse, and misuse in the treatment of patients with multimorbidity.

German Clinical Trials Register: DRKS00015718, registration date: 15th of October 2018

Strengths and limitations of this study

- affected patients and their relatives (who often function as informal caregiver) were interviewed in the focus groups
- focus group participants from two differently structured regions in Germany representing a wide spectrum of combinations of different diseases were queried
- focus groups with patients and their relatives (asking about positive and negative experiences with care) seem to be an effective tool to identify quality aspects relevant for QI development

INTRODUCTION

Our society is aging and higher life expectancy is associated with higher rates of chronic diseases. Care for patients with multimorbidity is likely to evolve into one of our most prominent challenges in the future [1,2]. Multimorbidity is strongly linked to functional limitations, lower quality of life and increase in health care utilization, costs and higher mortality [3,4]. Care for patients with multimorbidity is very complex [5] and therefore prone to deficits in quality and major (unintended) interindividual differences regarding the impact of illness and carer performance [6–9]. Multimorbidity creates many challenges to general practitioners (GPs) and affected patients alike, e.g. (too) short consultation times, polypharmacy, increased health care utilization, high treatment burden and self-management requirements as well as psychological distress [10,11]. Several decades of research and discussion have provided us with suggestions for management approaches in primary care to better address the needs of this patient group, inter alia, the Chronic Care Model [12,13] and the meta-algorithm [14] for treating patients with multimorbidity.

Generic standards for high quality of care are hard to define due to the infinite number of possible (combinations of) medical problems in patients with multimorbidity. Evidence-based standards relevant to patients with multimorbidity are urgently needed, because single disease clinical guidelines are for several reasons often inadequate for this patient population [10]. As long as the current state of health care cannot be mapped systematically, for example by using a set of quality indicators (QI) specific for multimorbidity, it remains impossible to compare the effects of interventions and health care models to optimize quality or to identify sectors, regions or health care providers needing improvement.

In Germany, the first point of contact in the health care system for people who fall ill is usually a general practitioner. GPs are usually licensed to provide care on the basis of contracts with the statutory health insurance (SHI) and are member of the corresponding association of SHI doctors. The statutory health insurance covers about 90% of Germany’s residents and is complemented by a private health insurance system. German GPs have usually completed five years of further training to be allowed to call themselves specialists in general practice/primary care. Patients are free to consult any GP unless they choose to enrol themselves in a GP contract (“Hausarztzentrierte Versorgung”). The contractually defined GP-coordinated care further strengthens the role of the GPs as guides and coordinators for the health care of their patients [15]. GPs refer patients to outpatient specialists or hospitals when further or specialized care is needed. There are more than 100 different types of patient record management software [16] and usually the patient records of different doctors are not linked, which means that their communication and coordination often relies on (referral/discharge) letters and patients’ reports.

Taking the patients' perspective into consideration is even more relevant when dealing with patients with multimorbidity. Every decision made concerning risks and benefits of treatments and interventions has to be weighed against individual impairments, comorbidities and gain in subjective quality of life [14]. Prioritization must take the whole range of biopsychosocial complexities into account and follow principles of patient-centred clinical management and decision making. Views on high quality health care often differ between patients and their health care providers [17,18]. For example, quality of care seems to be higher when process or intermediate outcome indicators are measured and lower when patient-reported experiences of care are reviewed [18]. Therefore patients can [19] and must be involved in guideline and QI development [20–23]. Studies show that this is not often the case [21] even though approaches to patient involvement in QI development, e.g. focus groups, exist and are considered to be of high value [20].

The MULTIqual project aims at the development of a quality indicator set which can be used to evaluate the current state of health care provided for patients with multimorbidity and to promote the implementation of treatment standards for future care. We conducted focus groups with patients with multimorbidity and their relatives to validate and amend a literature- and expert consensus-based set of QI by qualitatively surveying their views on health care quality.

METHODS

The MULTIqual project is a multi-centre mixed-methods project comprising a systematic literature review, focus groups, a two-stage expert consensus process and a quantitative survey with patients with multimorbidity and general practitioners. Following the COREQ [24] this paper presents the results of focus groups with patients with multimorbidity and their relatives conducted in Hamburg and Heidelberg and of the expert consensus on the qualitatively derived QIs. The details of the systematic literature review, expert panel, consensus process and quality indicator development process are not directly relevant for the work presented here, but can support the understanding of the whole project. A summary of the process can be found in suppl. File 1. An extensive description will be presented elsewhere (manuscript in preparation).

Participant selection and recruitment

We randomly selected the GPs from the register of SHI-accredited doctors of the city districts or within a radius of 25 km around the two study centers respectively. We invited the selected GPs to participate in our study and informed them in detail about the project if they were interested. Participating GPs were asked to recruit patients aged 65 and above with three or more chronic conditions that attended the practice at least once in the last three months. Patients with multimorbidity willing to participate were asked to invite close relatives to take part in the study as well. Exclusion criteria were insufficient knowledge of the German language and inability to give informed consent. Patients received an invitation containing study information, a response sheet and a reply envelope. Participants received an allowance of 30€ plus a reimbursement of travel expenses. Participants gave written informed consent for the focus groups to be recorded, transcribed and the data being published anonymously.

Focus group guide

Guide development was based on the literature review (e.g., [25]) and the research questions outlined above. As lay persons mostly relate to implicit experiential knowledge when defining quality criteria (e.g., [26,27]), we chose to question our focus group participants about their own positive and negative experiences with primary health care, changes in their health care needs and experiences due to multimorbidity and their vision of ideal primary care for people like them (see suppl. file 2 for 'patients' focus group guide'). With patients' relatives, the same topics were discussed in respect to the associated patient with multimorbidity (see suppl. File 3 for 'relatives' focus group guide').

Data collection

Either JS, CH, AB or KG had spoken to the participants on the phone, but had no other relationship with them. In 12/2018 and 01/2019 we conducted eight focus groups with patients with multimorbidity (city A =3, city B= 5) and three focus groups with patients' relatives (A=1, B=2) using the semi-structured guides described above. Two moderators facilitated the focus groups (NJP, JS, KG, AB, CH and TKl respectively) which lasted about two hours. Discussions were digitally recorded and transcribed verbatim by a trained research assistant following designated transcription rules. Accuracy of the transcripts was checked by the respective moderators. In order to protect the focus groups participants' identity, names and other identifying details were changed during transcription.

Data analysis

Data were analysed using the qualitative content analysis approach described by Kuckartz [28], following a realistic paradigm [29]. Coders (NJP, CH and JS) read all transcripts to familiarize with the data. Transcripts were broken down into fragments adopting different sizes ranging from part of a sentence to one or more paragraphs in relation to the segment length needed to understand the content and context of the relevant accounts. We created deductive codes representing the aspects of quality described in the literature-based QI set and selected by the expert panel and inductive codes when new aspects of quality emerged from the data (see below). We then subjected all transcripts to a second round of coding by a different coder. Coding was carried out with constant discussions between the three coders about the coded text passages and assigned codes. To ensure intersubjective reproducibility and comprehensibility [30], the results were presented to and discussed with the interdisciplinary workgroup 'qualitative methods' and the co-authors DL (postdoctorate, MD) and MS (professor, MD). Data was managed using MAXQDA 11 (Verbi GmbH).

Identification of additional patient relevant quality aspects and expert rating of deduced QI

We aimed to supplement the preliminary QI set extracted from a systematic literature review by QI based on patient-relevant quality aspects derived from the focus group data. A multidisciplinary research team (NJP, CH, KG, AB and JS) allocated subjectively important quality aspects from patients' and their relatives' views to the preliminary set of QI based on the literature review and identified important additional quality aspects where needed. Afterwards the research team transformed the additionally identified quality aspects into QI (including description, numerator, denominator, exclusion criteria etc.). These QI were presented by NP to an expert panel during an in-person meeting. The expert panel consisted of representatives of primary care, nursing, practice management, quality research methodology, social work, physical therapy, geriatrics, clinical pharmacology, social medicine and patient representatives. The in-person meeting took place on 1st February 2019. During the meeting NJP presented the focus group-material-based new QI to the expert panel. After a rating of relevance, strength of evidence and their potential for undesirable effects, the expert panel voted for keeping or rejecting the QI deduced from the focus group material via nominal group technique.

Patient and public involvement statement

Patients were involved in the recruitment of focus group participants (viz. their relatives). Patient representatives and representatives of relevant fields (see above) were involved in the rating and selection of QI. Apart from that there was no patient or public involvement in the study.

Researcher characteristics

Researchers' characteristics, beliefs and assumption influence qualitative research and data interpretation. NJP (♀): post-doc psychologist, experienced qualitative researcher (patient involvement in QI development, health care research focusing on general practice). JS (♀): psychologist/junior scientist. CH (♀): medical student. AB (♀): junior scientist, M.A. Health Information Management. DL (♀), KG (♀), JSz (♂), MS (♂): medical professionals, experienced post-doc researchers in the field of general practice and QI development.

RESULTS

Participants characteristics

We included 29 female and 18 male patients aged 65-84 years as well as three female and six male relatives (five spouses/four children) aged 49-78 years in five patient groups, and three relatives groups, respectively. Nine registered volunteers did not take part, with n = 3 due to acute health problems and n = 6 due to organizational difficulties.

Focus group-based additional quality aspects included into the QI set after the expert panel rating

Two focus-group based quality aspects were finally supported by the expert panel and included in the QI set.

Patient education / self-management

Patients consider it very helpful to be informed about their diseases and possible (self-) treatment and management strategies (for example, nutrition counselling). Daily disease management can be supported by specific information on self-management strategies, training in disease-related competencies (for example, measuring the INR value), addressing coping strategies and provision of knowledge for the patient.

> *"I took part in a course in [city] and have been monitoring my 'Quick' [prothrombin time] myself for over 20 years and I have a book and also keep a record. And I always took it with me to the hospitals and the doctors were amazed that they could see exactly how I did it and how I tested my 'Quick'. […] And I always write it down and then I dose the medication myself. No, I am still grateful to the doctor for giving me the tip that I can do the course how to measure my 'Quick' on my own […]."*
>
> *(city B, patient focus group A, paragraph 162-166)*

Regular updates of medication plan

Patients report to have been provided with medication plans and consider it very important for them to be up-to-date especially when taking a high number of different medications or when medication is prescribed by specialists. Some patients always have copies of their medication plan at hand in case of an emergency and it would be considered helpful if this plan was accessible electronically on the health insurance card.

> *"This is also from the GP, right? It's a medication plan. So you know when to take it and so on. One should know that. But also that you can show it, if someone asks: 'What are you taking?' Oh god, yes, what am I taking? What's it called again? It just changed again, hasn't it? Well, I know it, but it's also good for the other doctors if they have something printed and to be able to see exactly what she needs, what she takes, how often and when […]. So, it is very pleasant when GPs do something like that. Gives you a certain amount of security."*
>
> *(city A, patient focus group B, paragraph 251-253)*

Focus group-based additional quality aspects not included into the QI set after the expert panel rating

Two other indicators were not supported by the expert panel and not included in the final QI set.

Regular check-ups

Patients with chronic diseases see a need for regular check-ups as it would allow for early detection of health deterioration and they know these procedures from the disease management programmes, e.g. for diabetes or COPD. They value the regular contact with the GP at fixed appointments.

> *"[...] if you take these medications regularly and then say: "We'll have a general check-up once every two years" – I think that's not enough. I think it should be every year. The status should be checked once in a while, if I'm taking these pills regularly."*
>
> *(city A, patient focus group C, paragraph 97)*

General practitioner coordinated care

Patients appreciate the GPs to coordinate their care which involves for example writing referral letters for specialist visits (and the GP receiving medical reports), having a network of specialists at hand, planning preventive measures and keeping track of medications and their interactions and side effects. Patients who describe their relationship with their GP as trusting, want all information on their health care to converge at their GPs' practice.

> *"[...] when the diagnoses are made and the GPs know what's going on, then they should actually act as a control center and have the possibility to coordinate everything."*
>
> *(city A, patient focus group A, paragraph 264)*

> *"That's a given in our practice. He always wants to give you referrals because he wants to have doctor's letters. Otherwise he says he doesn't have an overview. And I think that's very, very good."*
>
> *(city B, relatives' focus group A, paragraph 66)*

Literature-based quality aspects supported by focus groups

Table 1 gives an overview of quality aspects identified in the literature review and supported by both focus groups and expert consensus and shows supporting quotes from the focus groups. Descriptions of categories shown table 1 follow below.

Table 1: Quality aspects identified in the literature and supported by focus groups and expert panel ratings

Patient-related factors	Assessment of biopsychosocial support needs	“So for me, I would like to see myself not only as a body, or only as organs, but as a complex human being. That’s very important for me, […] this union of body, mind and soul." (*city B,* patient focus group A, paragraph 70) “This is certainly an aspect that the doctors should [...] actually take a closer look at again: What is the situation at home? Does the person need support? Do we have to organize something?” (*city B,* relatives' focus group A, paragraph 91)
	Involving partners, family and caregivers	“Perhaps this could be discussed in a phone call with relatives, so that I am informed about the current situation, what is pending or how the medication maybe, yes, what I have to pay attention to as a caring relative and, as I said, if this is okay for my mother, as I know that she is not informed at all.” (*city B,* relatives' focus group A, paragraph 174)
Physician-patient-interaction	Shared decision-making and mutual agreement on treatment goals	“A doctor's sole decision: (.) "Do this or that" - if the patient doesn't agree, it is pointless (...). He won't do it anyway. (..) And that's why I think that those issues really need to be discussed together. And determined together what is possible for the patient. Not everything is possible." (city A, patient focus group A, paragraph 468) “[...] we discussed it [...] at eye level in a VERY thorough conversation, so that we decided on the therapy regimen together, which I follow, and use take control of the disease." (city A, patient focus group A, paragraph 21)

	Information about medication and potential benefits and harms of treatment	“It's important to me [...] that I get information in an [...] understandable way about what is going on with me and how this could be treated.” (city A, relatives' focus group A, paragraph 357) “And then that in some cases he may explain the disease. Not the disease, but the measures, that's the way I wanted to put it. But then we come back to the time factor again. But in some cases, as I said, it is done this way. So that you get a little more time and get information about what is actually going on and what you can do about it. Or against it.” (*city B,* relatives' focus group B, paragraph 98) “But it’s just that when I get pills and it says this and that and you don’t even know what it’s for. […]” (*city B,* patient focus group C, paragraph 43)
	Medication review and documentation of adverse drug reactions	“Especially in the case of multiple chronic diseases, I find it extremely important that the general practitioner explains to me that the drugs are compatible, that there is no interaction or that it is possible that they will cancel each other out or even worsen the condition, as in the case of my mother [...]”(*city B,* relatives' focus group A, paragraph 69) “I also consider close monitoring of drug effects and side effects important. Because there are side effects that one does not even register, which develop so insidiously. So it's a good thing that experts with their backgrounds check for possible side effects and say: “Watch this, something is happening to you, that doesn't fit in or it's a side effect”.

		Because I only read the package insert when I really have something and suspect a side effect. I do not read them in advance. Because then you don't take the drug." (city A, relatives' focus group A, paragraph 357)
	Written treatment plan	"I packed a little something from my management. I don't know if you know anything like that, here is a blood sugar diary for people on insulin. This is from the diabetes clinic. It contains all my data, every record, both blood sugar levels and blood pressure and then the insulin dose. And I also check my weight and write it down here, so I always keep everything together. And I take this to my general practitioner as well as to the other doctors, for example to the eye specialist. And I think that's good." (city A, patient focus group A, paragraph 167-168)
Context and Organizational Structures	Comprehensive care documentation	"I think [...] to keep an overview of the attending specialists is actually very important. Because [...] when I go to the eye specialist or ear, nose and throat specialist, and the GP doesn't even know this, and usually doesn't get a medical report from them either, then he is actually missing out […] on important information. I could have glaucoma, or whatever. And he doesn't even know about it and he doesn't even know what kind of medication you might have to take. […]" (city A, patient focus group A, paragraph 466)
	Training programmes addressing	"Whereby I have to say with my GP's joint practice, you can't complain. So there are two [employees], I think, they are still trained nurses. That's how long they've been at it. They are REALLY competent. And I'd say they already

	management of patients with multimorbidity	have a certain diagnostic instinct. They can tell when someone comes in with swollen eyes, whether it's just a flu-like infection or a real flu, that he should perhaps be isolated." (city A, relatives' focus group A, paragraph 108) "Well, of course we have the problem that we have more and more elderly people who are sick, and have multiple diseases. And we have fewer and fewer GPs. So, I think it would be a very good care model if we had, for example, registered physicians who specialize in geriatrics. I think it would be a good care model if we had general medical training, with additional specialization, for example in mental health. I would prefer geriatrics and that these doctors with such training, who also have many, many or mostly older patients, are given more time. That perhaps, there are also these reference numbers, what they can charge. Because, we have to get there, because there are more and more elderly people, that they would get the possibility, the aspect of time and if it is only five minutes. Five minutes is a lot per patient. But that is of course an idle wish [...]" (*city B,* patient focus group A, paragraph 85)

Assessment of biopsychosocial support needs

Patients expressed a need for the GP to have a holistic view on the patient's health problems and needs. They underlined the importance of not only seeing and treating physical symptoms, but also the overall picture of medical and psychosocial aspects of the patient's situation. They consider it important for the GP to have at least basic information on the patient's background and personal history. Sometimes house calls can be necessary for a realistic judgement on biopsychosocial support needs for example for elderly people with beginning dementia.

Involving partners, family and caregivers

Relatives of people with multimorbidity often appreciate the GPs' willingness to communicate with them and support them in the process of giving care. Support and advice are often desperately needed by informal caregivers of persons with multimorbidity, especially if dementia is an issue. GP's awareness of informal caregivers' problems and concerns is important and could for example be addressed by offering consultation hours for relatives and other informal caregivers.

Shared decision-making and mutual agreement on treatment goals

Shared decision-making to find a customized treatment approach for individual patients is highly appreciated by the focus group participants. Communicating, informing and deciding on treatment regimens and goals on a par with the patient are seen as essential for increasing adherence and patient satisfaction. Patients value the freedom to set their own priorities and make decisions based on their values and preferences concerning their health and health care behaviour. They appreciate their GPs supporting them in this approach and the autonomy this respect gives them.

Information about medication and potential benefits and harms of treatment

Our focus group participants did not differentiate clearly between information and advice on their diagnosis, disease or condition and risks, medications (for example indication, dosage and interactions) or non-pharmacological treatments and their benefits and potential side effects. They emphasize the importance of detailed and comprehensible information on all these aspects. Either way, some stated not to be interested in very detailed descriptions of potential risks and side effects. The amount of information given must be tailored to the patient's needs even though these consultations might need more time than usually budgeted.

Medication review and documentation of adverse drug reactions

Medication reviews are highly acclaimed by the focus group participants. Patients and their relatives wish for the GP to check for interactions regularly especially with medication prescribed by others and over-the-counter (OTC) drugs. They expressed criticism of the high numbers of prescribed drugs and low engagement of health professionals to actively inquire about drug-related problems and to search for highly tolerable medications. Patients focus less on the thorough documentation of adverse drugs reactions than on their monitoring and handling. They wish for the GP to detect signs of adverse effects and monitor them for example through regular follow-ups.

Written treatment plan

Focus group participants' recognize the value of written treatment schedules that include overviews on scheduled health care appointments plus instructions, e.g., whether they have to appear with an empty stomach for bloodwork. They emphasized the advantages of automated recalls systems. Another focus was on recorded treatment protocols, e.g. keeping a blood pressure journal or a diabetes log book containing measured values and other relevant parameters. Patients proposed using digital solutions for facilitating care coordination between different providers.

Comprehensive care documentation

The vast majority of the focus group participants consider comprehensive care documentation as a vital part of high quality care, emphasizing importance of the exchange of information on diagnostic testing or examination results and prescribed medication, giving the GP the opportunity to coordinate care and consult the specialist about the patient’s treatments. Patients report that the responsibility for this exchange is often in the patients’ hand, being the ones to take care of specialists’ letters being issued to the GP. Under the premise of data security, patients would support a digital exchange of doctor’s letters, but sometimes doubt the ‘digital competencies’ especially of the older generation of physicians.

Training programmes addressing management of patients with multimorbidity

Patients put emphasis on the competencies of the practice team. For medical assistants this means for example being experienced in taking blood samples or administering vaccinations or injectable medications. Another aspect is the ability to triage patients according to the severity and urgency of their treatment needs. GPs should engage in continuous medical education, be up-to-date on actual research results and technological advances. Participants valued additional training in the field of geriatrics or psychology and proposed regular supervision and peer consultation for complex problems in multimorbid patients.

Literature-based quality aspects not supported by focus groups

Table 2 gives an overview of quality aspects identified in the literature review and supported by the expert panel but not accounted for in focus groups. As this paper focuses on the focus group result, these quality aspects are described extensively elsewhere (manuscript in preparation).

Table 2: Literature-based quality aspects not supported by focus groups

Patient-related factors	Screening for depression
	Proactive pain assessment
	Monitoring of pain management
	Addressing financial support needs
	Quality of life assessment

	Assessment of symptom burden
	Establishing patient preferences
Physician-patient-interaction	Identification of patients with multimorbidity
	Assessment of treatment burden
	Monitoring adherence to treatment
Context and Organizational Structures	Assigning responsibility for coordination of care

DISCUSSION

Main results

By asking patients with multimorbidity and their relatives in focus groups about their experiences with primary health care we were able to identify important quality aspects from their point of view and derived four new patient-relevant QI to date not represented in guidelines or the literature on quality of care in multimorbidity. Out of these, two QI concerning regular updates of written medication plans and patient education and fostering self-management were supported by the expert panel. On the other hand, regular check-ups and GP-coordinated care were not supported by the expert panel. Half of the literature-based QI, for example assessment of biopsychosocial support needs, establishing patient preferences and shared decision-making, were supported by participants' accounts, while more technical domains regarding assessment and treatment regimens were not covered in the focus groups.

Strength and limitations

To obtain a comprehensive picture of aspects of quality of care from the affected persons' point of view we asked not only patients with multimorbidity, but also their relatives (often informal caregivers) in separate groups. Focus group participants were recruited in two very differently structured regions of northern and southern Germany and represent a wide spectrum of combinations of different diseases. We therefore assume that our results might be cautiously generalizable to patients with multimorbidity in primary care all over Germany. However, the experiences reported by patients with multimorbidity and their relatives in the focus groups may to some extent be specific to the German healthcare system. In other countries, such as the UK, for example, medication reviews and the provision of medication information are the responsibility of pharmacists. Our results should not be transferred to other countries without cautious reflection, as the organisation of health care systems and the implementation of (primary) care differ between Germany and other countries.

Reflecting and evaluating own experiences is dependent on representation of different perspectives, lived experiences and group interaction, and must be fragmentary, as participants were lay persons regarding health care (quality). Therefore, it did not seem feasible to ask the participants to propose QI. Instead, we focussed on positive and negative experiences with primary care and derived patient-relevant QI indirectly. As many accounts can be matched to QI derived from the literature and half of the newly developed QI were supported by expert consensus this methodology seems to be plausible and practicable.

Although the questions focussed on experiences regarding the related patients with multimorbidity, the results from focus groups with relatives show that for some participants it was difficult to focus on their role as (caregiving) relative. Many participants referred to their own health care experiences being affected by multiple conditions themselves, which reflects the spectrum of issues and challenges in the field as the prevalence of multimorbidity increases in older age [31].

Discussion of results and comparison with existing literature

The complexities of managing multimorbidity are widely known [10] and there is a growing amount of literature on interventions for improving outcomes in patients with multimorbidity [11,32]. Different approaches to tackle the challenges of caring for patients with multimorbidity were discussed, from the Chronic Care Model [13], a systematic collection and review of interventions [32] and quality standards [33] to a German meta-algorithm [14], but a quality indicator set involving the perspective of affected patients and their (potential) informal caregivers is still missing.

Since 2016, patients enrolled in statutory health insurance in Germany have a right to be provided with a recorded medication plan if they are prescribed at least three different long-term medications, which is very much appreciated by persons with multimorbidity in our study and elsewhere [34]. If patients consent, these data can be saved to the electronic health card or record to allow for a standardized digital exchange of this information of these data between providers [35,36]. Despite preferring a written medication plan and stating the problem of insufficient communication between prescribing physicians, participants of our focus groups judged this incorporation ambivalently as they saw problems concerning data safety and confidentiality [37] as well as (older) GPs digital literacy.

Patients' with multimorbidity wish for patient education, fostering of self-management and periodic check-ups might arise from their experiences with patient education and regular control of, e.g., blood values, respiratory function and blood pressure during the structured disease management programmes (DMP, e.g., [38]) that many patients with diabetes, COPD or heart failure take part in. DMP for single diseases and lone-standing self-management interventions for patients with multimorbidity have shown to be helpful (e.g., [39,40]), which supports the patient-education QI (see also [19]). While a recent systematic review supports the importance of monitoring treatment effects and clinical parameters [11], this is no plea for generalised periodic check-ups without a definite indication.

The proposition of a GP-coordinated care was not supported by the expert panel as this care model is not yet sufficiently embedded within routine care in Germany [41], although §73 SGB V [42] makes way for general practitioner-centred primary care (coordination) since 2003, which is also highlighted in the policy paper of the German College of General Practitioners and Family Physicians from 2012 [43].

Literature-based QI validated by the focus group focus mostly on aspects that address interpersonal communication, holistic treatment approaches and processes that allow patients to make their own choices based on comprehensive information. This aligns our findings with the wide scientific consensus that the treatment of patients with multimorbidity should be informed by a patient-centred approach [19,44–46]. The majority of the quality statements proposed by National Institute for Health and Care Excellence (NICE [33]) align with the indicators resulting from our study (e.g., “assessing values, priorities and goals”, “care coordination” and “reviewing medicines and other treatments”). All measurement frameworks seem to have one thing in common: taking shared-decision making into account as central aspect of patient-centred care [47].

An explanation for the lack of support for the QI dealing with screening and assessment issues in the focus groups might be due to the participants’ perspective as individuals and end users of care structures and processes. Qualitative methods are mostly able to elicit patients’ personal experiences with and views on health care (processes) and laypersons are seldom confronted with meta-level issues directed at groups of patients and not individual patients.

Other projects aiming at the development of quality frameworks in multimorbidity predominantly focussed on outcome measurement [48–50]. Scientific evidence on generic health outcome measures to assess quality of care for patients with multimorbidity is still lacking. In the light of patients’ with multimorbidity individual goals and priorities it proves difficult to define outcome indicators suitable for all. Keeping that in mind, our QI set addressing mainly care processes and covering a broad range of care domains is evidence-based and seems to be very adequate for the evaluation of quality of care for patients with multimorbidity.

Future research

Primary care patients (≥65 years) and their GPs will be questioned using standardized patient reported outcome measures (related to the identified QI) and other instruments (measuring behaviour described in the identified QI) to study validity and applicability of the developed set of QI. The definite set of QI will be determined based on the study results.

Practical implications

The QI set finally developed in the MULTIqual-study can be used as a framework for assessing the quality of care in the German health care system. It will facilitate implementation of treatment standards, increase the use of existing guidelines [14,51] and help to reduce over-, under- and misuse of healthcare resources. The QI set will serve as a reference framework for future evaluations of complex interventions and care models for patients with multimorbidity.

CONCLUSION

Our study has demonstrated that focus groups with patients and their relatives add important aspects in QI development, should be incorporated by default in QI development processes and constitute a reasonable addition to traditional QI development [19,20]. Future challenges lie in the adoption of these quality criteria as practical and valid standardized measures and their implementation in primary care.

Author contributions

MS, DL, JSz: Acquisition of funding for and conception, design and supervision of the study. AB, KG, NP, JSc: moderation of focus groups. AB, KG, CH, NP and JSc: data analysis and interpretation. NP: drafting of the manuscript. AB, KG, CH, DL, JSc, JSz, MS: critical revision of former versions and final approval of the manuscript.

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Data availability statement

The data generated and analyzed during the current study are not publicly available due study's assurances to participants that the full raw focus group data would not be shared publicly, and that all attempts would be made to maintain confidentiality. We named the people who are responsible for data analysis to the focus group participants in the written consent and they did not agree to the sharing of the full raw data.

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Competing Interests

None declared.

Ethics Approval

Ethics approval was obtained from the Ethics Committee of the Hamburg Medical Association, (10th September 2018, PV5846), from the Clinical Ethics Committee Heidelberg (19th December 2018, S-665/2018), and the Medical Association of Baden-Wuerttemberg (13th November, B-F-2018-096).

Consent to participate

Participants gave written informed consent to participate in the study and for the focus groups to be recorded, transcribed and the data being published anonymously.

Consent for publication

Not applicable.

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Appendix to: Pohontsch et al. Quality of care for people with multimorbidity: A focus group study with patients and their relatives. BMJ Open 2021

Literature review and rating/consensus process

Prior to the focus groups a systematic literature search was conducted in different electronic databases. References of relevant articles were reviewed to identify missed relevant publications. Recommendations for clinical management of patients with multimorbidity were extracted and translated to quality indicator candidates. After an online rating of relevance, strength of evidence and their potential for undesirable effects, the interdisciplinary expert panel voted for keeping or rejecting the potential QI via nominal group technique.

Guideline for Focus Groups with Patients

„Experiences of people with three or more chronic conditions and their relatives with primary care“

1. Entry: introduction round

Before we discuss your experiences, I would like to do a small round of introductions.

1.1 Please introduce yourself briefly one by one. Please state your name, age and your chronic diseases.

2. Experiences

Introductory question: What has changed for you in your primary care compared to the past, since you no longer have only one, but three or more chronic diseases?

2.1 Positive experience with primary care

I would like to ask you to tell us about your positive experiences with primary care.

2.1.1 What experiences have you had so far with your GP where you felt particularly well taken care of? Please think of your experiences as a patient with multiple chronic diseases at the same time.

2.1.2 What expectations do you have for your GP and his team?

2.2 Negative experiences with primary care

2.2.1 What experiences with your family doctor have you had so far where you felt that you were not well taken care of? What happened? Please also give reasons for your negative evaluation.

2.2.2 What would you have wished for in connection with this negative experience?

3. Vision for primary care

3.1 If you pause for a moment and think about the situation of people with multiple chronic diseases in general: Which problems do you think exist in the primary care of people with several chronic diseases?

3.2 Please tell us what good primary care for patients with multiple chronic diseases looks like or should like.

3.3 Imagine if **you** could design primary care for people with three or more chronic diseases yourself. What would ideal primary care look like for someone like you?

4. Conclusion of the discussion

Now we have come to the end of the first part of the discussion. We have talked about many things. Is there anything that we have not yet addressed, but that is still important to you and that you would like to add?

Break

5. Prioritization

During the break we have collected the aspects you find important for the primary care of people with multiple chronic diseases. Now we would like to ask you to evaluate these aspects and to give 1 to 4 points depending on their importance: 4= very important, 3= rather important, 2 = rather not important, 1= not important.

Now we would like you to explain why those aspects which you have given 4 points are so important to you.

Guideline for Focus Groups with Relatives

„Experiences of people with three or more chronic conditions and their relatives with primary care “

1. Entry: introduction round

Before we talk about your experience, I would like to do a small round of introductions.

1.1 Please introduce yourself briefly one by one. Please state your name, age and the chronic illnesses that affect your relative.
1.2 Please also briefly describe your relationship with your relative, who has multiple chronic conditions, and the extent to which you are involved in their care.

2. Experiences

Introductory question: In your opinion and your experience, what has changed in primary care compared to the past since your relative no longer has not only one but multiple chronic diseases?

2.1 Positive experiences with family doctor care

Now I would like to ask you to tell us about your good experiences with the family medical care of your relative, who is affected by several chronic diseases.

2.1.1 What experiences have you had so far where you would say that the GP was taking particularly good care of your relative?

2.1.2 What expectations/wishes do you have for the medical care of your relative who is affected by multiple chronic diseases?

2.2 Negative experiences with primary care

2.2.1 What experiences with medical care have you had where you would say that you and your relative was not well taken care of? Please also give reasons for your negative evaluation.

2.2.2 What would you have wished for in connection with this negative experience?

3. Vision of optimal primary care

3.1 If you pause for a moment and think about the situation of people with multiple chronic diseases in general: Which problems do you think exist in the primary care of people with several chronic diseases?

3.2 Please tell us what good primary care for patients with multiple chronic diseases and their relatives looks like or should like.

3.3 Imagine if **you** could design primary care for people with three or more chronic diseases yourself. What would ideal primary care look like? What would you wish for as a family member?

4. Conclusion of the discussion

Now we have come to the end of the first part of the discussion. We have talked about many things. Is there anything that we have not yet addressed, but that is still important to you and that you would like to add?

Break

5. Prioritization

During the break we have collected the aspects you find important for the primary care of people with multiple chronic diseases. Now we would like to ask you to evaluate these aspects and to give 1 to 4 points depending on their importance: 4= very important, 3= rather important, 2 = rather not important, 1= not important.

Now we would like you to explain why those aspects you have given 4 points are so important to you.

COREQ

"Quality of care for people with multimorbidity – A focus group study with patients and their relatives"

Topic	**Item No.**	**Guide Questions/Description**	**Reported on Page No. (Comment)**
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	p. 7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	p. 8
Occupation	3	What was their occupation at the time of the study?	p. 8
Gender	4	Was the researcher male or female?	p. 8
Experience and training	5	What experience or training did the researcher have?	p. 8
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	p. 6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Researchers introduced themselves and the study at the beginning of the focus group meetings.
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	p. 8
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	p. 7
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p. 6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	p. 6
Sample size	12	How many participants were in the study?	p. 9
Non-participation	13	How many people refused to participate or dropped out? Reasons?	p. 9
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	in the department's meeting room
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	Trained research assistant taking notes
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	p. 6/9
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See suppl. files 1+2

Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	No, not applicable
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	p. 7
Field notes	20	Were field notes made during and/or after the interview or focus group?	No, not applicable
Duration	21	What was the duration of the inter views or focus group?	Approx. 120-135 minutes
Data saturation	22	Was data saturation discussed?	No, because theoretical saturation is a concept originally developed within Grounded Theory. Later, it was termed data/thematic saturation for other qualitative methods. While the concept of saturation has helpfully been translated for other qualitative approaches it is not appropriate to impose it on all instances, for example conversation analysis and qualitative content analysis (using purposive, not theoretical sampling).
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	No. We did not return the transcripts to the focus group participants as this does not seem to be the usual procedure in studies using focus groups and qualitative content analysis and would have meant an unduly demand from the patients.
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	p. 7
Description of the coding tree	25	Did authors provide a description of the coding tree?	p. 9-19
Derivation of themes	26	Were themes identified in advance or derived from the data?	p. 7
Software	27	What software, if applicable, was used to manage the data?	p. 7
Participant checking	28	Did participants provide feedback on the findings?	No. In health services research, where the data collection is an one-off exercise, participant checking might be more trouble than it is worth, especially in respect to the expenditure of the participants time. We therefore choose to ensure intersubjective reproducibility and comprehensibility by discussing the results with an interdisciplinary workgroup for qualitative methods.
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	p. 9-19 and table 1
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes, we think that data and findings presented are consistent, but also think that it is the readers'/reviewers' right/duty to judge about that.
Clarity of major themes	31	Were major themes clearly presented in the findings?	p. 9-19
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	p. 9-19