Patient-centred ambulatory healthcare for people aged 80 and over

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Summary

People aged 80 and over are the fastest-growing age group in most industrialised countries. On average, this life phase is characterised by a significantly higher burden of morbidity, limitations in daily activities, medical and dental treatment needs and phenomena such as multimorbidity and frailty. However, individual ageing and health trajectories are highly heterogenous. This challenges current healthcare systems that are still primarily organised around acute care occasions. Ambulatory healthcare is in particular demand as the sector closest to people's lives and the guarantor to enable ageing in place. By now, ambulatory healthcare providers already face considerable work burdens and are the first to encounter the challenges of this demographic change, especially due to lacking adaptations on the health system level.

So far, care models for the improvement of ambulatory healthcare for older people have mainly been developed without their participation. These models primarily focused on structural elements such as coordination to manage the complexity of conditions, with mixed results. A more recent approach to redesigning healthcare is the concept of patient-centred care, which puts the patients with their individual goals, expectations and living realities at the centre of healthcare design. Patient-centred care has gained widespread recognition and can now be considered an overall goal for healthcare. However, few studies have systematically incorporated older people's views to design patient-centred care. In particular, the group of the oldest old, aged 80 and over, were seldom of interest, despite their rapid growth and special healthcare needs. Moreover, the topic of their oral health and healthcare was rarely included in researching health services. Additionally, the investigation of the perspectives of their healthcare providers is needed to understand the practical reality and to advance the support of an appropriate health workforce for an ageing population.

Consequently, this dissertation aimed at investigating what matters in developing patient-centred ambulatory healthcare for people aged 80 and over. Three dissertation projects (DPs) were conducted to examine the views of community-dwelling people aged 80 and over and their healthcare providers regarding ambulatory healthcare comprehensively as well as indepth.

In DP1, a systematic review of qualitative studies on the views and experiences of people aged 80 and over regarding ambulatory healthcare was conducted. A meta-synthesis of the 22 included primary studies resulted in the development of three core motives that older people have regarding healthcare: feeling safe, feeling like a meaningful human being, and maintaining control and independence. Parallel to that, a meta-summary of the same set of studies was conducted, resulting in 23 specific desirable features of ambulatory healthcare that were systematically appraised on their confidence in the evidence using the tool GRADE CERQual.

In DP2, the findings from DP1 were used to further investigate desirable features of ambulatory healthcare from the perspective of community-dwelling people aged 80 and over in Cologne, Germany. In qualitative interviews using a semi-structured interview guide, 22 participants

were asked about their perspectives on general ambulatory healthcare and oral healthcare. The interview transcripts were analysed thematically and resulted in a framework of 16 characteristics of good healthcare for the very old, incorporating oral healthcare equally. The study also revealed that older people particularly value and wish for trustful care relationships, that they are rarely aware of their oral health matters, and that they frequently encounter negative stereotypes of older age in the context of healthcare.

In DP3, physicians and dentists providing ambulatory healthcare in the state of North-Rhine Westphalia, Germany, were researched. Using a qualitative survey design in the mode of online data collection, they were asked about their perceptions and views on their routine work and interactions with patients aged 80 and over. The results from 77 cases analysed with the approach of structuring qualitative content analysis showed that the healthcare providers found working with the very old particularly challenging due to their medical complexity and non-medical demands, such as psychosocial matters.

The results from all three DPs were taken together to describe and explain what is relevant in the design of patient-centred ambulatory healthcare for the very old. Apart from features of such healthcare, the dissertation discusses the broader implications in referring to the understanding of health, ageing and the role of healthcare, the further development of patient-centred care and the building of a healthcare workforce for the ageing population.

Zusammenfassung

Personen, die 80 Jahre oder älter sind, stellen die am schnellsten wachsende Bevölkerungsgruppe in den meisten Industrienationen dar. Im Allgemeinen geht diese Lebensphase mit einer höheren Morbiditätslast, Einschränkungen in den täglichen Aktivitäten, medizinischer und zahnärztlicher Behandlungsbedürftigkeit und Phänomenen wie Multimorbidität und Frailty (Gebrechlichkeit) einher. Nichtsdestotrotz sind die individuellen Alterns- und Gesundheitsverläufe sehr heterogen. Infolgedessen stellt diese Altersgruppe die Gesundheitssysteme, die noch immer primär auf die Versorgung akuter Krankheitsfälle zugeschnitten sind, vor Herausforderungen. Vor allem der ambulante Versorgungssektor mit der größten Nähe zum täglichen Leben der Menschen und als Garant dafür, zuhause alt werden zu können, ist hierbei gefragt. Bisher sind es im Besonderen die ambulant tätigen Ärztinnen und Ärzte, die bereits einer hohen Arbeitslast unterliegen und die diese Herausforderungen primär schultern, da es an adäquaten Antworten auf der Ebene des Gesundheitssystems fehlt.

Versorgungsmodelle mit dem Ziel der Verbesserung der ambulanten Gesundheitsversorgung für die Älteren wurden bisher hauptsächlich ohne deren Beteiligung entwickelt. Sie konzentrierten sich vornehmlich auf strukturelle Elemente wie die Koordination zum Management komplexer Gesundheitszustände, und resultierten in gemischten Ergebnissen. Einen neueren Ansatz zur Umgestaltung der Gesundheitsversorgung stellt das Konzept der patientenzentrierten Versorgung dar, in dem die Patientinnen und Patienten mit ihren individuellen Zielen, Erwartungen und Lebensrealitäten ins Zentrum der Versorgungsgestaltung gestellt werden. Das Konzept hat umfassende Anerkennung erhalten und kann mittlerweile als übergeordnetes Ziel der Gesundheitsversorgung betrachtet werden. Allerdings berücksichtigten bisher nur wenige Studien die Ansichten Älterer in der Gestaltung patientenzentrierter Versorgung. Vor allem die über 80-Jährigen wurden selten adressiert, trotz des Wachstums dieser Bevölkerungsgruppe und ihrer besonderen Gesundheitsbedürfnisse. Zudem wurde das Thema der oralen Gesundheit und Versorgung bisher selten in die Erforschung ihrer Versorgung mit einbezogen. Zusätzlich ist es notwendig, die Perspektiven der sie versorgenden Ärztinnen und Ärzte zu untersuchen, um die praktische Versorgungsrealität zu verstehen und ihre adäquate Unterstützung für eine alternde Gesellschaft voranzutreiben.

Hier setzte die vorliegende Dissertation an. Ihr Ziel war es, zu untersuchen, worauf es in der Entwicklung patientenzentrierter ambulanter Versorgung für Menschen ab 80 Jahren ankommt. Drei aufeinander aufbauende Dissertationsprojekte (DP) wurden durchgeführt, in denen die Sichtweisen von über 80-Jährigen in der Häuslichkeit und den sie versorgenden Ärztinnen und Ärzten in Bezug auf die ambulante Gesundheitsversorgung in der Tiefe sowie in der Breite untersucht wurden.

In DP1 wurde ein Systematic Review basierend auf qualitativen Studien zu den Sichtweisen und Erfahrungen über 80-Jähriger in Bezug auf die ambulante Gesundheitsversorgung durchgeführt. Eine Metasynthese der 22 eingeschlossenen Primärstudien resultierte in der Entwick-

lung von drei Grundmotiven Älterer in Bezug auf die ambulante Gesundheitsversorgung: sich sicher zu fühlen, sich als bedeutsamer Mensch wahrgenommen zu fühlen sowie Kontrolle und Unabhängigkeit zu bewahren. Parallel dazu wurde eine Metasummary der Studien erstellt, die in 23 spezifischen wünschenswerten Merkmalen ambulanter Gesundheitsversorgung resultierte. Diese 23 Merkmale wurden zudem systematisch bezüglich des Vertrauens in ihre Evidenz mithilfe des Tools GRADE CERQual eingeschätzt.

In DP2 wurden die Ergebnisse aus DP1 genutzt, um die wünschenswerten Charakteristika ambulanter Gesundheitsversorgung aus der Perspektive über 80-Jähriger in der Häuslichkeit in Köln, Deutschland, vertiefend zu untersuchen. Im Rahmen qualitativer Interviews, in denen ein semi-strukturierter Interviewleitfaden verwendet wurde, wurden 22 Teilnehmende zu ihren Perspektiven auf die allgemeine sowie auf die zahnärztliche ambulante Gesundheitsversorgung befragt. Die Interviewtranskripte wurden thematisch analysiert und ergaben ein Framework von 16 Charakteristika guter Gesundheitsversorgung für die Ältesten, wobei die zahnärztliche Versorgung gleichberechtigt berücksichtigt wurde. Die Studie zeigte zudem, dass Ältere besonders den Aufbau vertrauensvoller Versorgungsbeziehungen wünschen, dass sie sich kaum der Bedeutung ihrer Mundgesundheit bewusst sind, und dass sie in Bezug auf das höhere Alter häufig auf negative Stereotype in der Gesundheitsversorgung treffen.

In DP3 wurden Ärztinnen und Ärzte sowie Zahnärztinnen und -ärzte mit ambulanter Tätigkeit in Nordrhein-Westfalen, Deutschland, untersucht. Mithilfe eines qualitativen Surveydesigns im Modus einer Onlineerhebung wurden sie zu ihren Wahrnehmungen und Sichtweisen ihrer täglichen Arbeit und Interaktionen mit über 80-Jährigen befragt. Die Ergebnisse aus 77 eingeschlossenen Fällen wurden mit der strukturierenden qualitativen Inhaltsanalyse ausgewertet und zeigten, dass die Ärztinnen und Ärzte die Arbeit mit den Ältesten aufgrund ihrer medizinischen Komplexität, aber auch nicht-medizinischen (z. B. psychosozialen) Anliegen als besonders herausfordernd empfinden.

Die Ergebnisse aus allen drei Dissertationsprojekten wurden gemeinsam betrachtet, um zu beschreiben und zu erklären, worauf es in der Gestaltung patientenzentrierter ambulanter Gesundheitsversorgung für die Ältesten ankommt. Abgesehen von Merkmalen einer solchen Versorgung diskutiert die Dissertation die weiterführenden Implikationen in Bezug auf das Verständnis von Gesundheit, Altern und die Rolle der Gesundheitsversorgung, die weitere Entwicklung patientenzentrierter Versorgung und den Aufbau adäquaten Gesundheitspersonals für die alternde Bevölkerung.

List of Abbreviations

ADL Activities of daily living

CCM Chronic care model

CERQual Confidence in the evidence from reviews of qualitative research

EU European Union

GP General practitioner

HCP Healthcare provider

IADL Instrumental activities of daily living

JDRM Job demands – resources model

NICE National Institute for Health and Care Excellence

OECD Organisation for Economic Co-Operation and Development

PCC Patient-centred care

SDM Shared decision-making

SHI Statutory health insurance

SOC Sense of coherence

WHO World Health Organization

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1. Introduction

Demographic change, meaning the ageing of populations, is a global phenomenon. In 2017, 962 million people worldwide were aged 60 and over. This number has more than doubled since 1980, is increasing further, and is expected to reach 2.1 billion people by 2050 [1]. Among these older people, especially the group of those aged 80 and over is growing significantly. Globally, 137 million people are aged 80 and over, and by 2050, this number is expected to triple to 425 million [1]. Europe is the continent already more strongly affected by this development. In the European Union (EU), the proportion of people aged 80 and over is expected to reach 13% by 2070 [2]. This comes with a development towards more and smaller households, with approximately a third being single households and especially older women living alone [3]. It is also associated with a growing burden of (multiple) chronic diseases, as the most important factor in healthcare costs. Multimorbidity, frailty, and certain limitations in daily activities are becoming more common, especially among the oldest population [4-7]. This development has been known for a long time, but in the *World Report on Ageing and Health*, the World Health Organization (WHO) criticises the fact that health systems are still not adequately organised:

Although the world is experiencing a rapid transition towards ageing populations, health systems generally have not kept pace. Most health services around the world have been designed around acute care models that are poorly aligned with the dominant health issues of older age. This failure in care is exacerbated by age-based discrimination and by ignorance of the priorities and needs of older people [4, p. 99].

Two developments are considered necessary to ensure healthcare meets the ageing population's needs and enables the best possible health: strengthening ambulatory healthcare and providing patient-centred care.

Ambulatory (i.e., primary, outpatient) healthcare plays a considerable role in caring for older adults since it is usually their first point of contact with healthcare. To age in place and remain in their home environment, avoiding institutionalisation, is a common important goal for most older people and a politically pursued goal [4, 8-11]. Firstly, to age in place means that older people can be safe in a familiar environment and that they can maintain autonomy and independence [10]. Therefore, comprehensive, proactive healthcare is required for older people, and this is usually provided in ambulatory healthcare sectors. Secondly, institutional settings such as hospitals are not considered suitable to manage complex and chronic conditions or to provide prevention and health promotion and are also more costly [11-13].

Patient-centred care (PCC) emphasises the centrality of patients' perspectives, especially their individual preferences, goals and needs [14, 15]. This is understood as a contrast to the acute care orientation of most health systems and hence is particularly suitable to address the challenges of ageing populations and their chronic conditions [4]. The concept has gained great

recognition and to date is understood as an ideal of healthcare, being taken up in research and policymaking in Germany and internationally [4, 11, 15-17].

However, holistic implementation of PCC and involvement of patient views have not yet been achieved [17, 18]. In particular, the views of people aged 80 and over, as the population group increasingly formative for healthcare, remain rarely researched or incorporated in the development of care models and PCC. While studies have investigated the preferences and views of people aged 60 and over (e.g., [19, 20]), age groups are often not further differentiated. It is hence unclear to what extent people aged 80 and over – the *oldest old* compared to the *younger old* – have been incorporated or whether their views differ. Moreover, several of the studies indeed investigating the oldest focused on those who are care-dependent or living in institutionalised settings (e.g., [21, 22]). Since the overarching goal is to avoid care dependency and institutionalisation, it becomes apparent that studies on the community-dwelling oldest are needed to ensure ageing in place as well as possible. Moreover, such studies need to incorporate a comprehensive view of health and healthcare, comprising all areas relevant to maintain health and well-being. This points for instance to the explicit incorporation of oral health and healthcare, a topic often neglected concerning older people, despite its important role in overall health and well-being and considerable dental treatment needs in older age [23-25].

Additionally, to fit the reality of healthcare and grant adequate provision of health services to the oldest, it is necessary to also understand the perspectives of healthcare professionals caring for them. For instance, some studies have researched nurses' attitudes toward older people or general practitioners' (GPs) understanding of complexity in older patients (e.g., [26, 27]). However, it remains unclear how the breadth of healthcare providers, such as the range of physicians, specialists, and dentists, in ambulatory healthcare perceive working with them or what they define as good healthcare in old age.

This dissertation was designed to address these gaps. The overall aim of the dissertation is to describe and explain what matters in developing patient-centred ambulatory healthcare for people aged 80 and over by investigating the perspectives of community-dwelling people aged 80 and over and of the physicians and dentists caring for them. Exploring patients' and healthcare providers' day-to-day-world, their experiences, needs, preferences, decisions and priorities is an important part of health services research and particularly useful to understand "the last mile" of health services provision [28]. As such, this dissertation aims to inform and facilitate the development and design of ambulatory healthcare in the future. This is understood both as a necessary reaction to the challenges of demographic development and as an active pursuit of the ideal of PCC [29].

Figure 1 provides a visual overview of the composition of this dissertation. In Chapter 2, the theoretical background and state of research on health from the age of 80 and over are presented. Chapter 3 presents the status, challenges and proposed solutions for ambulatory healthcare. Chapter 4 outlines the development of the concept of PCC and its possibilities in healthcare for older people. Chapter 5 then presents how the current healthcare situation makes healthcare

providers on the first line of ambulatory healthcare encounter professional challenges. Consequently, the objectives and methods of this dissertation, including a summary of the four publications from three research projects as the core of this dissertation, are presented in Chapter 6. The publications themselves are outlined in Chapter 7, while the full publications are available in the appendix. The results are brought together to build a framework of ambulatory healthcare in older age in Chapter 8. It discusses further the results regarding their meaning for the understanding of health and well-being in older age, patient-provider interactions and how caring for the oldest is a challenging task for healthcare providers. In Chapter 9, these areas of discussion are used to show implications for research and practice regarding 1) the meaning of ageing and health, 2) the further development of PCC and care models for the very old, and 3) the building of a well-equipped healthcare workforce. Finally, the methodological strengths and limitations are discussed in Chapter 10, and a general conclusion from the dissertation is presented in Chapter 11.

Patient-centred ambulatory healthcare for people aged 80 and over Growing very old: Possibilities of patient-centredness in Characteristics of and perspectives on healthcare for older people old age and ageing **Background** Ambulatory healthcare encountering Healthcare professionals providing the very old: Current status and healthcare for the very old challenges in ambulatory healthcare Research gap and derived To describe and explain aim of the What matters in developing patient-centred ambulatory healthcare dissertation for people aged 80 and over? What matters to people aged 80 and over What are the views and What are the regarding ambulatory perspectives of characteristics of healthcare? ambulatory healthcare desirable ambulatory Three providers on caring for Which features of health and oral dissertation people aged 80 and healthcare from the ambulatory healthcare projects perspective of people over? are preferred by people aged 80 and over? aged 80 and over? Conducted 2019 -2022 Systematic review of Qualitative interviews **Qualitative online** qualitative studies survey with communitydwelling people aged 80 with ambulatory → Meta-synthesis healthcare providers → Meta-summary and over Patient-centred ambulatory healthcare for people aged 80 and over Understanding health, well-being and the role of ambulatory healthcare in older age Results to be discussed Interactions between older people and healthcare providers Providing healthcare for people aged 80 and over: A challenging task Debating the understanding of ageing and health Implications to Developing and implementing patient-centred care models be discussed Building a healthcare workforce for ageing populations

Figure 1: Graphical overview of the dissertation

2. Growing very old

As in Europe, a particular growth of the oldest population occurs in Germany. A "triple ageing" can be observed:

- an increase in the absolute number of people aged 60 and over,
- an increase in the relative number of people aged 60 and over compared to those aged 20 and younger, and
- an increase among people aged 60 and over, with an especially strong increase in people aged 80 and over [30].

While approximately 4.4 million people were aged 80 and over in 2013 (equalling around 5% of the whole population), this proportion is expected to increase to 12-13% (nine million) by 2060 [31]. In the following, the consequences of the demographic development regarding health and well-being in older age are described.

2.1 Health and morbidity in old age

One of the most important questions regarding this development is whether it is associated with an *expansion* or, by contrast, with a *compression of morbidity*, a question without a clear answer. As the WHO summarises, despite good analyses in the past 30 years the findings have been inconsistent. While severe disability seems to be slightly declining to constant, comorbidity and chronic diseases have increased [4, 32], potentially meaning that there "may be a small reduction in some forms of disability at a given age, although it is unlikely to be keeping up with the added years people are living" [4, pp. 49-51]. In general, the likelihood of having health-related problems or a chronic condition increases with increasing age [33-35].

One of the most important developments regarding ageing populations' health is multimorbidity, often defined as the persistence of two or more chronic conditions [5]. The occurrence of multimorbidity increases with age and is prevalent among at least half of the people aged 65 and over [5]. While socioeconomic status and gender are known to play important roles in the prevalence of multimorbidity, factors such as genetic background, lifestyle or environment have not yet been sufficiently researched [5, 36]. Multimorbidity is associated with higher health services use and poorer quality of life [5, 37]. It also often results in multiple medication prescriptions, hence complex medication regimes and potentially inappropriate medications or adverse events [38]. In Germany, the highest number of defined daily doses of medication can be found in the group of 80-to-85-year-olds [39]. Moreover, older patients can have problems with handling complex medication regimes due to limitations in hearing, reading, understanding and memorising instructions. This is particularly critical due to a common lack of continuity of medication between different healthcare sectors or settings and older people's higher vulnerability to side effects [40].

Another critical phenomenon in older people is frailty. Frailty is the result of interacting physical and cognitive deteriorations [6, 41]. It is age-related and progressive, while often "silent" in its early stages, and poses a risk for negative health outcomes [6, 36, 42]. A strong increase in frailty can especially be observed around the age of 80 [42, 43]. While frailty is estimated to be prevalent in 15.7% of people aged 80 to 84 in industrial countries, among people aged 85 and over, the prevalence reaches 26.1% [44]. In a Canadian population health survey among community-dwelling people aged 15-102 years, frailty was prevalent among 2% of people aged 30 and younger, and 22.4% among those 65 and older, including 43.7% of people aged 85 and older [42]. It was also found that antecedents of frailty already start in middle age and that accumulated health deficits are rather a representation of *ageing* instead of age [42]. Hence, whether frailty as a representation of biological age is a more appropriate measure for expected health limitations compared to chronological age is discussed [41].

The afore-described phenomena are also linked to disability, which can be defined as "difficulty or dependency in carrying out activities essential to independent living, including essential roles, tasks needed for self-care and living independent in a home, and desired activities important to one's own quality of life" [6, p. 255]. A large representative study on health and living conditions in Germany examined whether the participants had limitations in performing activities of daily living (ADL) such as hygiene, toilet use and eating. Moreover, limitations regarding instrumental activities of daily living (IADL) such as housekeeping, telephoning or medication intake were investigated [7]. Overall, 13.4% of women and 9% of men aged 80 and over had at least one serious limitation in ADL, which is a large increase compared to just under 5% among men and women aged 65-79 years, especially regarding the ADL of getting up, bathing or showering [7]. The results were similar for IADL, where 35.9% of women and 21% of men aged 80 and over had at least one serious limitation, compared to approximately 12% and 8% respectively among the younger age group. It was also found that limitations in ADL and IADL are associated with health-related impairment, chronic illness, limited mobility, lower educational status and income, and living alone [7]. While limitations in ADL and IADL do not necessarily imply care dependency, they pose a greater risk for it [4].

Another special phenomenon closely related to old age are geriatric syndromes. Geriatric syndromes describe conditions among older persons that cannot be assigned to specific clinical categories or underlying causes; rather, they present complex interactions [36, 45]. Common examples are falls, urinary incontinence, dizziness or delirium. Frailty is also described as a geriatric syndrome [36, 45]. Geriatric syndromes are multifactorial; they break the categorical boundaries of organ systems or medical disciplines and are therefore particularly challenging in the practice of healthcare. Joint risk factors seem to be older age, impaired cognition, function, and mobility [45]. Geriatric syndromes can strongly affect the quality of life and predict care dependency [36, 45].

Hence, it is not surprising that older age is associated with higher health service use [12]. Outpatient and inpatient service use shows an increase with age, while the trend is to consult

more different specialists with older age [46, 47]. However, outpatient health service use is generally high in Germany, with an average of nine to ten contacts per person per year (dental care not included). Although use starts to increase in middle age, it is relatively stable around the age of 80 years [46]. But the need for care increases significantly around the age of 80, with approximately 70% of people receiving home care [46].

2.2 Oral health in old age

A component seldom integrated into the considerations of older people's development of health conditions and needs is oral health. However, oral health plays an important role in people's general health, well-being and quality of life: It ensures that people can properly chew and eat, are free of pain and can uninhibitedly participate in social interactions such as conversations or having a meal with others [23, 24, 48, 49].

As Kossioni et al. describe for Europe, older people's oral health is often poor. This is due to common oral diseases, for instance, periodontal disease and caries, but also hyposalivation due to a high medication intake, impaired oral function or conditions related to having a denture [23]. This is in line with the findings of the Fifth German Oral Health Study, in which 1133 people aged 75 and over were examined. Nearly all of them had caries experience, and 90% had periodontal disease [25]. Moreover, the vast majority (92.6%) had a denture, and around 40% reported problems with chewing [50]. Further studies from Europe reveal comparable results. For instance, a cross-sectional study in France examining oral care needs of older people (median age 93 years) showed that of the dentate participants, the majority had a prevalence of plaque and calculus and at least one untreated decayed tooth, and maladaptation of removable prosthesis [51]. It was also found that older people are seldom aware of their preventive and curative dental care needs [51]. In the USA, community-dwelling and home-bound older people were also found to have considerable dental care needs [52-55]. In general, dental medicine has focused more strongly on prevention in recent years, overall resulting in the maintenance of more teeth in the life course [56], but this success is seemingly not sustained among the oldest.

Concerning the correlation between oral health and general health and well-being and the considerable dental treatment needs in older age, it is surprising that utilisation of oral healthcare services declines remarkably in old age [25, 51]. In an examination of five European countries, Holm-Pedersen summarises the following factors resulting in low dental service use in older people: limited availability and organisation of services, limited price subsidy, a lower number of remaining teeth and a negative attitude towards oral health (services) [57]. Often, older people, but also a variety of healthcare providers such as nurses, physicians or informal carers, are not aware of oral health matters or do not consider them a priority [23, 48, 51, 58]. Apart from transportation issues to reach dental services due to limited mobility [23, 57, 59, 60], the personal threshold in accepting help with oral hygiene seems to be high [58].

2.3 The diversity of ageing trajectories

The findings on older people's health so far have shown that several conditions are increasingly common, especially from the age of 80 and over, and that they have the potential to impact people's well-being. However, ageing is not a linear process of decline, and despite the significantly higher burden of morbidity, older age is not an inevitable phase of deficits, illness and loss. Although physical decline occurs over time, it is only loosely explained by chronological age and older people show diverse trajectories of health [4]. These trajectories may start from different levels, e.g., depending on socioeconomic status, but during the life course, also in older age, various "setbacks and recoveries" can occur [4, p. 65]. Moreover, the number or description of diagnoses, typically higher in older age, does not necessarily mean that older people's well-being or quality of life is low. As a current French study among community-dwelling people aged 80 and over found, although nearly all participants reported at least one health problem, health-related quality of life was mainly good in most dimensions, particularly regarding self-care and remaining autonomous, and regarding depression and anxiety [35]. The older people were mostly satisfied with their lives, although they were concerned about their future and health-related quality of life. This illustrates how objective and subjective indicators of a good life and well-being in older age may show remarkable discrepancies. For example, as Plugge showed in a representative sample of people aged 80 and over in North-Rhine Westphalia, Germany, only 9% of this group aged "successfully" when considering objective criteria such as having no major disease or disability. Nevertheless, 79% reported being satisfied overall with their life and over 90% reported having a positive to very positive ageing experience [61]. By contrast, having a good or very good subjective health status significantly decreased from the age group 65-79 years to 80+ years, according to a representative Germany-wide study of health, especially among women (55.3% in women 65-79 compared to 42.5% among women aged 80 and over) [33].

What can be learned from these findings is that ageing is highly heterogenous, with "winners" confirming the compression of morbidity and "losers" confirming the expansion of morbidity [30]. Ageing and older age do not automatically equal decline and illness, and many factors of health, social, and environmental systems can influence the course of peoples' health trajectories [30, 36]. This is confirmed by the various health states among the older population group across Europe, especially concerning socioeconomic, gender and educational differences [34, 36, 43, 61]. Hence, approaches to effective and meaningful health services need to be even more strongly oriented to people's individual circumstances, optimisation of their health trajectories and the most important goals and outcomes regarding their daily lives [4]. Consequently, the frequently demanded paradigm shift in medicine becomes more urgent in light of the ageing population. As the specifically outlined phenomena of complex interactions between conditions in older age show, the challenges ahead cross the well-known and still solidly maintained borders of distinct medical categories and disciplines [43].

2.4 Theoretical perspectives on being well in old age

Another common conclusion from the reports on older people's increasing burden of morbidity or physical decline is that ageing generally is a final life phase of decline, deterioration, decreasing well-being, and loss [62]. However, while medical interventions frequently focus on specific functional deficits that should be improved, single improvements are unlikely to lead to greater improvements in quality of life [62]. Moreover, despite physical and partly cognitive deteriorations compared to younger age groups, subjective well-being and quality of life do not necessarily decline equally and the chance is good of still being well and having a high quality of life in older age [61].

On this matter, different theoretical approaches from psychology and gerontology explain how older people act and design their lives to achieve well-being. One classic approach is the disengagement theory proposed by Cumming and Henry. They assumed that particularly the certainty of imminent death shapes older people's perceptions, while their strength and resources decline due to physical deterioration [63, 64]. Hence, the older person withdraws from societal roles in agreement with societal expectations, e.g., the person retires. The accordance between the withdrawal and societal measures (such as a regular retirement age) leads to life satisfaction in the older person and further disengagement [63, 64]. Although this theory has been quite popular, it can now be considered refuted based on empirical findings that point to the positive correlation between (social) activity and well-being in older age [64].

A more positive and currently dominant approach is the *model of selective optimisation and compensation* by Baltes and Baltes [65]. The model describes how individuals are confronted with changed circumstances and challenges in the older life phase, such as declines in capabilities, but that they still have developable, expandable, flexible resources to unfold, for instance via learning and training. The model assumes that through conscious and unconscious processes, older people select new developmental goals and preferences that are currently meaningful to them and that they optimise their strategies, learn and train to achieve these goals, compensating for certain losses or deteriorations to finally maintain well-being [62, 65].

Another perspective is offered by the approach of *developmental tasks* in different phases of life. In this approach, ageing means sequentially mastering newly occurring developmental tasks, and successful mastery leads to well-being and satisfaction [62]. These tasks are influenced by a variety of individual, biological, and societal, but also historical, political or economic factors, and especially society-shaped expectations regarding the adequate choice of developmental goals in different age phases [62]. One early conceptualisation of developmental tasks was provided by Havighurst. He especially considered the biological context of ageing (physical decline, loss, impending death) and formulated developmental tasks in late adulthood such as accepting one's life and new roles and confronting the topic of death and dying [62, 66]. A more positive approach to developmental tasks was provided by Peck, who took into account personality development and, more in line with the model of selective optimisation and compensation, described tasks including the choice of new meaningful goals and success or

well-being measures [62, 67]. As Martin and Kliegel argue, the confrontation with new circumstances and roles and the end of certain roles such as in working life have the potential for individual freedom to choose and develop personally meaningful goals. However, biological factors such as health-related problems and impairments also play important roles [62].

What has been described so far is the higher burden of morbidity and health-related impairments in the older and especially the very old population, which has consequences for the provision of healthcare. However, these bundles of conditions are not inevitable, and more importantly, they do not necessarily imply that old age is a phase of constant deterioration, loss or low well-being. Consequently, two main challenges arise for (ambulatory) healthcare for the oldest: meeting the higher needs resulting from morbidity and health-related decline and providing care that encounters great heterogeneity in older people's life courses and health trajectories.

On this basis, the following chapter provides an overview of the current situation of ambulatory healthcare in Germany, general suggestions on how to encounter the demographic change in healthcare, and the research status on ambulatory care models that were developed to improve healthcare for older people so far.

3. Ambulatory healthcare encountering the very old

In light of the afore-described increased burden of morbidity and especially outpatient health service use by older people, the ageing population can especially be considered a challenge for the ambulatory healthcare sector as usually the first and the long-term point of contact. As Berman defines, "the term 'ambulatory care provision' refers to the individuals and organisations that deliver personal health care services on an outpatient basis" [13, p. 792]. This includes a range of healthcare providers and organisations, e.g., GPs and specialists in their practices and outpatient settlements of hospitals [13]. In the following, the circumstances of ambulatory healthcare in Germany are described, followed by a presentation of challenges and recommendations from research and policy. Afterwards, an overview of care models already developed to improve ambulatory healthcare for older people is given and discussed.

3.1 Ambulatory healthcare in Germany

In Germany, a strong organisational separation exists between the ambulatory healthcare sector, which provides outpatient care, and the hospital sector, which provides inpatient care, and the distinction between reimbursement modes is clear [68]. In the ambulatory healthcare sector, physicians and dentists offer their health services mainly in their practices (in the following: healthcare providers, HCPs). They are represented and organised by different associations of statutory health insurance (SHI) for physicians or dentists, respectively (Kassenärztliche Vereinigungen, Kassenzahnärztliche Vereinigungen) [68, 69]. These associations represent HCPs who are allowed to offer and invoice health services based on the SHI. In recent years, the number of HCPs under the SHI has increased, especially the share of specialists. In contrast, the share of GPs has decreased, although several attempts have been made to promote and strengthen GP care [68-70].

Germany has one of the most comprehensive health services catalogues covered by the SHI, by which almost 90% of the German population is insured [68-70]. However, private co-payments for additional or higher quality services are possible and especially common for oral healthcare services [69]. Although GPs have a certain coordinating role, there are generally no gatekeepers. Patients can usually freely choose physicians and dentists, which is probably a driver of Germany's comparatively high outpatient and inpatient services use [68-70].

As the Organisation for Economic Co-operation and Development (OECD) summarises, Germany's per capita expenses for health are among the highest compared to EU member states, at 11.2% of the gross domestic product. However, inefficiencies exist due to fragmented healthcare structures, while health outcomes are rather average [70]. Great potential exists in prevention, health promotion and care coordination, especially regarding people with chronic conditions. Among the possibilities to improve efficiency, the OECD suggests a reduction of hospital overutilisation, expansion of ambulatory healthcare, improvement of integration, care coordination and evaluation of health services, and improvement of eHealth services [70].

Strengthening ambulatory healthcare is the main improvement recommendation made by the OECD, as it is usually the first point of contact and can provide a comprehensive consideration of patients' conditions and living circumstances [32, 40, 70].

3.2 Challenges and recommendations for ambulatory healthcare

Not only Germany but also most other industrialised countries face challenges due to demographic change, especially the fast growth of the oldest population group. Although progress has been made, states worldwide have failed to adapt their health systems to the increasing number of chronic and complex conditions [4, 71]. It is frequently stated that most health systems are still based on acute, episodic care that is reactive rather than proactive and provides fragmented instead of integrated care [40, 71, 72]. The need to reform becomes more urgent since the demographic change does not only have a health perspective. A sociocultural change also results in fewer younger people being able to care for the older or to pay into the insurance scheme, more one-generational and single households and more employed women. As a result, informal and lay resources decrease, increasing the demand for professional support [12, 32]. While young patients with rather acute and limited occasions for seeking healthcare fit the healthcare system quite well, older people constantly challenge the system and healthcare providers with their more complex and long-term issues [4].

Hence, while HCPs have been trained in providing specialised care to address single conditions, this is not sufficient anymore. They have to learn new skills, focusing more strongly on care across professional boundaries and prerogatives [71]. Simultaneously, these increasing demands do not meet an increasing workforce of HCPs. As in other European countries, particularly the German ambulatory healthcare sector lacks physicians, mainly GPs [68]. Despite the rapid demographic change, the offer of physicians generally has not changed; despite some increases, working hours per week have also decreased [73]. However, it is also still unclear how many more physicians would be needed to provide appropriate healthcare for older people or how the number needed could be decreased by other means [73].

Apart from increasing the number of HCPs, several claims and suggestions have been made concerning reforming healthcare systems in response to population ageing, with a particular focus on ambulatory healthcare [40]. The need to shift healthcare from orientation to acute care occasions towards management and care of chronic conditions is seen as inevitable, and it is required to realign the organisation of health services, including financing and reimbursement [40, 74, 75]. Firstly, one significant area concerns the fragmentation of health services and therefore, a need to improve care coordination and integrate healthcare services, sometimes also connected to the implementation of case management, is often stated [4, 20, 32, 40, 74, 76, 77].

Secondly, frequent suggestions concern the development of interdisciplinary professional teamwork and new collaboration models, possibly including new distribution and shaping of all healthcare professionals' roles and tasks [40, 71, 74, 75, 77, 78]. Moreover, it was found necessary to address the extent and breadth of education and training contents of healthcare

professionals, especially focusing on the shifted requirements of older patients, comprehension of their complex needs and the chronic and mostly incurable nature of their matters, incorporating interprofessional education and training [20, 74, 75, 77, 78].

Thirdly, the possibilities of prevention and health promotion to delay or avoid serious conditions or disability as long and much as possible are referred to, resulting in an expected reduction of the burden of morbidity, healthcare workload and cost. Healthcare systems and professionals should focus on prevention and restoration regarding (older) people's health status and the maintenance of individually meaningful functions and abilities and social participation [20, 32, 40, 74, 79].

3.3 Existing care models for ambulatory healthcare in older age

Several care models and concepts have been developed to address the described challenges and suggestions. Table 1 shows a summary of care models developed or applied for older people in the ambulatory healthcare sector that were identified from the published literature. The overview allows for conclusions about the direction and elements of these care models.

Table 1: Overview of care models for the improvement of ambulatory healthcare

Care model	Components of the care model		
Care for Seniors Model [80] Canada	 case finding (identification of at-risk seniors) assessment and recommendations regarding episodic and chronic care system navigation and self-management support 		
Chronic Care Clinics [81] USA	 visit with physician and nurse to plan chronic disease management pharmacist visit patient self-management/support group 		
Chronic Care Model [82] USA	 self-management support clinical information systems delivery system redesign decision support healthcare organisation community resources 		
Continuous Care Model [83] Iran	 orientation meeting sensitisation session including education control session to evaluate care and health behaviour evaluation of the continuous care process after the intervention 		
Coordination of Professional Care for the Elderly (COPA) [84] France	 strengthened role of the primary healthcare provider multidisciplinary primary care team using case managers integration of primary medical care and specialised care through using community-based geriatricians communication systems 		
EMBRACE [85] The Netherlands	 combination of Chronic Care Model elements and classification of care needs, based on the Kaiser Permanente Triangle self-management support delivery system design 		

Care model	Components of the care model		
	 decision support clinical information systems EMBRACE classification profiles: A) robust, B) frail, C) complex care needs 		
Expanded Chronic Care Model [86] Canada	 self-management/development of personal skills delivery system design/re-orientation of health services decision support information systems building healthy public policy creation of supportive environments strengthening community actions geriatric assessments by practice nurses: geriatric assessments, 		
[87] The Netherlands	 tailored care plans, agreement on a final care plan, follow-up and evaluation management by expert geriatric teams: quality management of care/expert knowledge transfer, multidisciplinary consultation, building and maintenance of local networks of care organisations 		
Geriatric Patient- Aligned Care Team (GeriPACT) Model [88] USA	 single point of contact for primary geriatric care coordination of care, personalised proactive care, reflexive team behaviour multidisciplinary core team (provider, nurse care manager, clinical associate, administrative associate) support of social workers, clinical pharmacists and other healthcare professionals 		
Geriatric Resources for Assessment and Care of Elders (GRACE) Model [89] USA	 GRACE support team (nurse practitioner, social worker) conducts geriatric assessment at the patient's home GRACE support team meets with GRACE interdisciplinary team (geriatrician, pharmacist, physical therapist, mental health social worker, and community-based services) to develop an individualised care plan GRACE support team discusses and adapts the plan with the patient's primary care physician GRACE support team implements and coordinates the plan using electronic medical records and longitudinal tracking systems 		
Guided Care Model [90] USA	 services provided by registered nurses and primary care physicians home-based assessment of patients' needs and goals evidence-based care planning proactive monitoring care coordination transitional care coaching for self-management caregiver support access to community-based services 		
IHSC Model for Frail Older People [91] China	 in-depth assessments regarding health and social well-being (provided by nurses or health workers) development of personalised care plans (possibly in consultation with further healthcare professionals) coordinated care (provided by social care providers) 		

Care model	Components of the care model		
Integrated Care Pathways [92] Canada	 assessment of needs, risk and protection factors data collection summary and identification of goals planning of interventions from a client-centred view coordination, delivery, and follow-up identification of variances, review and adjustment of plans 		
Interprofessional Model of Practice for Aging and Complex Treatments (IMPACT) [93] Canada	 interprofessional team and education (family physicians, community nurses, pharmacists, physiotherapists, occupational therapists, dietitians, community social workers) assessment of patient history, functioning, concerns, goals and perspectives team discussions, development of interprofessional care plan follow-up 		
MediCaring Model [94] USA	 development of longitudinal, patient-driven care plans provision of medical care tailored to frail older people incorporation of health, social, and supportive services monitoring and improvement of the model by a board representing community interests 		
Patient-Centred Medical Home [95] USA	 patient-centred primary care integrated population management value-care systems quality outcomes value-based reimbursement 		
Preventive Home Visit Model [96] Japan	 preventive home visits by community care nurses, care managers or social workers, every six months comprehensive care needs assessment individual recommendations for further support 		
Regionales Versorgungsmodell Geriatrie (Regional Geriatric Care Model) [97] Germany	 case-based, cross-sectoral case management case assessment and management provided by geriatric nurses development of a care plan consultation with GPs or hospital care providers monitoring and support via phone 		
Silver Network Project [98] Italy	 single entry centre geriatric assessment, integration and coordination of health and social services by a case manager multidisciplinary team involved in care planning (geriatrician, social worker, nurse, physiotherapist) 		
Systems Addressing Elder (SAFE) Care Model [99] USA	 screening identification of risk comprehensive interprofessional assessments (primary registered nurse, social worker, pharmacist, frailty team physician) interprofessional SAFE care team recommending the care plan documentation and communication to the care team and the physician follow-up and development of post-acute recommendations 		
Walcheren Integrated Care Model [100] The Netherlands	 GP as coordinator of care and single entry point GP assesses frailty patients receive a visit from a nurse practitioner performing further assessments 		

Care model	Components of the care model	
	 discussion of assessments in the multidisciplinary team (GP, nurse practitioner, nurse home doctor, other professionals) development of a treatment plan together with the patient and caregivers case management provided by a nurse practitioner evaluation in multidisciplinary meetings 	

Note: The care models were identified in a selective literature search in electronic databases to provide an overview of currently published models developed specifically for the ambulatory healthcare of older people. The age of the target groups differed, starting from around the age of 50 years. The components of the care models are presented as they are described in the publications.

A first interesting finding is that a considerable number of care models is based on the Chronic Care Model (CCM) developed by Bodenheimer et al. in 2002 [82], for instance, the expanded CCM [86], the Geriatric Care Model [87], EMBRACE [85] and the Guided Care Model [90]. Critiquing the "tyranny of the urgent" [82, p. 1775], the founders of the CCM pointed to the growing number of people having at least one chronic condition, and effectively gained attention for the necessary shift from acute to chronic care. The CCM incorporates healthcare organisations, the healthcare system and the communities in which healthcare is embedded [82]. An important overall feature is the productive interaction between an informed, activated patient and a proactive healthcare team [82, 101]. Consequently, the CCM is already a good approximation of patient-centred principles and highlights the necessary development of acutely oriented healthcare.

However, its applicability in the context of ageing populations, especially for very old people, should be questioned. This is first because the CCM mainly refers to single chronic conditions. Although it is more suitable for multimorbidity, it does not clearly incorporate or discuss how care should be organised or handled in the case of multiple conditions, with even more care sectors and care professionals involved. Moreover, despite a significant association between chronic conditions or multimorbidity and age, multimorbidity cannot be equated with older age. As has been described, health trajectories are not linear, and ageing is related to complex developments, all of them highly individual. The CCM and most of the subsequently developed models do not provide guidance on how to ensure that relatively fit older people can stay autonomous and free from limitations in abilities as long as possible. Moreover, patients' oral health, and consequently, the inclusion of oral health professionals, was seldom considered.

As can be seen in the models, a certain consideration of patients' individual preferences, priorities, and goals is especially represented by elements such as self-management support and the development of needs-based or individualised care plans. However, most elements in these models focus on care coordination and interdisciplinary teamwork, case management and several different assessments, often regarding functions. Hence, progress has especially been made regarding the organisation of health services and healthcare professionals, trying to overcome professional and sectional boundaries. On this matter, chronic care models in primary care could show decreases in costs and use [72]. This was also found in a systematic review

investigating multicomponent interventions: most innovations improved primary care access (e.g., via home visits or broader contact times), followed by financial changes such as additional payments, teamwork, technological interventions or strategies for patient self-management [102]. By contrast, dimensions of relationship-building going beyond the necessary communication to gain information on treatments are rarely included. Therefore, "productive interactions" as in this development seemed to focus on healthcare structures. So far, the developed care models are in line with the most dominant suggestions from organisations such as the OECD, as described above.

What is striking in examining the care models is that including older people in their development, e.g., as in the Walcheren Integrated Care Model [100], was an exception, although empowering patients and involving them in decisions otherwise was a frequently stated goal. Therefore, important elements from their point of view could be missing, especially considering their heterogeneity. This was also discussed as an explanation of why some care models fail to show expected outcomes such as quality of life [87]. A study in the Netherlands conducted by van de Pol et al. with primary care providers, nursing home residents and community-dwelling older people found potentially conflicting ideas and expectations among the different stakeholders regarding what good primary care is [103]. Consequently, "realising a successful care intervention is an undertaking that requires mutual understanding of the expectations and goals of all parties involved" [103, p. 5]. Generally, little research has been done on how the care models impact patient or provider satisfaction or other outcomes subjectively relevant to them [102].

What brings together all these requirements and is more frequently directly demanded is putting the patient in the centre of healthcare interactions and models, hence, to design and practice of PCC. PCC organises care around patients' individual needs, priorities and goals. Moreover, it enables the involvement and active participation of patients in their care plans, implementation and decision-making and enhances autonomy, ultimately resulting in the maintenance of health and abilities, reduction of resource waste, and patient empowerment to reach the best possible trajectory of health and ageing [4, 40, 75, 77].

4. Possibilities of patient-centredness in healthcare for older people

In the following, the origins and development of the concept of PCC are described; the reasoning for the pursuit and implementation of PCC in healthcare for older people is then discussed.

4.1 Development of the concept of patient-centred care

One of the roots of PCC is the concept of *person*-centredness introduced by Carl Rogers in the field of psychology and psychotherapy. He describes that the core of his approach

is that the individual has within him or herself vast resources for self-understanding, for altering the self-concept basic attitudes, and his or her self-directed behaviour – and that these resources can be tapped if only a definable climate of facilitative psychological attitudes can be provided [104, p. 1].

Rogers describes conditions that form a "growth-promoting climate" [104, p. 1] for any situation in which the goal is the development of the person. Hence, the person develops a self-caring attitude and the climate brings change because living organisms have an actualising tendency [104]. In Rogers' philosophy, empathy, acceptance and especially communication comprising a holistic view of the person, shared information and decisions, and a sensitivity for the person's needs are central, always focusing on potentials, resources and ways to maintain individuals' autonomy [104-106].

Although person-centredness stems from psychology, Rogers states that these principles apply to all relationships between professionals and clients [104]. The concept has been widely taken up in healthcare, e.g., in the WHO's *Global Strategy on People-centred and Integrated Health Services*, providing a paradigm shift in the organisation and delivery of healthcare towards putting people in the centre [4, 11]. In comparing patient-centredness and person-centredness, Håkansson Eklund et al. found that both concepts involve empathy, respect, engagement, relationship, communication, shared decision-making (SDM), a holistic focus, an individualised focus, and coordinated care [107]. These have a lot in common, and their main differences stem from their development of different historical concepts. In patient-centredness, the goal mostly refers to the patient's *functional* life, while in person-centredness, it is about the individual's *meaningful* life [107].

One further early development of patient-centredness was forwarded by Balint and Balint. They described the common practice of *illness-oriented medicine*, primarily aiming at finding, diagnosing and treating a localizable defect [108]. By contrast, they proposed *patient-centred medicine* as another approach of medical thinking, in which

in addition to trying to discover a localizable illness or illnesses, the doctor also has to examine the whole person in order to form what we call an 'overall medicine'. This should include everything the doctor knows and understands about his patient; the patient, in fact, has to be understood as a unique human-being [108, p. 269].

Balint and Balint conducted several seminars with GPs, focusing on psychological issues that arise in general practice. They described how this challenged and sometimes even frustrated GPs, who were struggling with their profession in these cases, as they did not want to be or become psychotherapists [108]. Enid Balint explained how their research shifted from making GPs "detectives" to gaining an overall understanding of the patient and developing patient-centred medicine in which patients get what they need during the specific appointment [108].

Therefore, it can be said that *person*-centredness, originally developed in psychology, promoted the development of *patient*-centredness, which is the corresponding concept in the field of healthcare. While several further *centred* concepts were formulated (e.g., family-centredness, people-centredness), the main focus is on relationships and communication [109], in delimitation to deficit- and illness-oriented care or therapy. This dissertation refers to it as patient-centredness (PCC) because the concept is tailored to healthcare.

The next important step in the development of PCC was a publication by Mead and Bower in 2000, reviewing the empirical literature current at that time. Mead and Bower described that patient-centred medicine is different from the dominant biomedical model in five dimensions that especially represent aspects of the doctor-patient-relationship [110]:

- Patient-centred medicine takes a biopsychosocial perspective since many illnesses are
 not in line with disease taxonomies. Therefore, the patient must be involved to be
 understood as a whole, including health promotion instead of focusing only on acute
 care.
- Patient-centred medicine understands the patient as a person, as unique in his or her biography and personal meaning and concerns regarding the condition.
- Patient-centred medicine shares power and responsibility by building an egalitarian relationship despite the persistent competence gap between doctor and patient. The patient's preferences and needs are incorporated, and the patient gets involved.
- Patient-centred medicine builds a therapeutic alliance, meaning that the doctor-patient relationship is prioritised, including its cognitive and affective components.
- Patient-centred medicine also views the doctor as a person, taking into account his or her personal qualities, which influence the relationship and care [110].

Another milestone was the report *Crossing the Quality Chasm: A New Health System for the 21st Ccentury* by the American Institute of Medicine (IOM) in 2001 [111]. It claimed that next to the classical goals of healthcare to be safe, effective and equitable, improvement efforts should address the goal of PCC, meaning care "that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" [111, p. 6]. The IOM posed ten rules for the necessary redesign of healthcare, including the anticipation of patient needs while also being able to customise care to the individual's needs, values, choices and preferences [111].

So far, patient-centred care or medicine was found to be 1) normatively relevant and 2) a chance to address the challenges arising from the shift from acute to chronic care. This development

may have been linked to the development of consumerism in healthcare, and a shifting prioritisation from the principle of beneficence to the principle of autonomy [112].

Overall, the concept was frequently described and understood as the counterpart of the persisting concepts of doctor-centredness, illness-oriented medicine, disease-oriented medicine, paternalism or a biomedical model of care [113]. While increasingly discussed, clear conceptualisations of what PCC *actually is*, have been missing for a long time. Therefore, Scholl et al. published an integrative model of PCC in 2014, based on a systematic review and concept analysis from 417 publications [15]. The model identified 15 dimensions of PCC:

- consideration of essential characteristics of the clinician, the clinician-patient relationship, and the patient as a unique person and taking a biopsychosocial perspective (principles);
- clinician-patient communication, integration of medical and non-medical care, teamwork and teambuilding, access to care, coordination and continuity of care (enablers);
- patient information, patient involvement in care, involvement of family and friends, patient empowerment and emotional support (activities) [15].

In a subsequent assessment of the dimensions' relevance from the perspective of patients, *patient safety* was added as the 16th dimension, and all dimensions were found relevant from patients' perspectives [18]. This dissertation refers to this most current and comprehensive conceptualisation of PCC. Moreover, the term 'patient preferences', often referred to in PCC, is broadly understood as "what patients want from their healthcare", which has to be identified and made explicit [114, p. 168].

Overall, the different developmental efforts of PCC have made a clear distinction from the traditional disease-oriented organisation of healthcare, but whether PCC is the "better" concept remains to be discussed.

4.2 Reasoning for patient-centred care and implementation

In (morally) justifying research on and implementation of PCC, two main strands can be identified: 1) PCC as intrinsically the right thing, and 2) PCC as the basis for better outcomes [113]. From a deontological perspective, where principles are in line with the principles and norms of medicine, it can be argued that PCC as such is the right thing to do. PCC enables the incorporation of more information, thereby leading to better medicine [113]. However, it also strongly focuses on shared power, SDM and enablement of the patient's autonomy. Moreover, it takes into account HCPs' subjectivity and their individual qualities, which may affect the patient (e.g., lacking empathy) [113].

From a consequentialist perspective, PCC is desirable if it provides good outcomes [113]. Evidence of the outcomes of PCC is mixed regarding clinical outcomes, but positive for intermediate outcomes, also depending on the context and study design [115]. Overall, it can be claimed that PCC positively influences patient satisfaction and well-being, with indications

that PCC promotes mental health, quality of life and health status [115-118]. Among the intermediate outcomes, PCC positively influences self-management, empowerment, adherence, information collection, trust, and the patient-provider-relationship [115-119]. Although strong evidence for the improvement of clinical outcomes may be lacking, the consequentialist requirements for the promotion of PCC seem met when considering that

- the pathways between PCC and outcomes might not be direct and not yet well understood, and
- from a patient-oriented perspective, particularly outcomes that patients describe to be important to them, e.g., trust in the provider and feeling heard and valued, should be used for the evaluation [120].

No evidence seems to show that PCC would produce *worse* outcomes. Moreover, other outcomes, e.g., those incorporating the provider's or organisation's perspective that may indirectly influence the care process and the patient should be considered relevant. However, little research has yet been conducted to investigate whether outcomes such as providers' job satisfaction are influenced by PCC [116].

Between these two justifications, Duggan et al. also discuss PCC as a virtue. They point out the need to differentiate between PCC *behaviour* and PCC *attitudes*. The virtue consists in its focus on attitudes; it is learned through role models, mentors and teachers, and it cannot be as easily observed as behaviours. Internalising PCC as a virtue and developing PCC attitudes influences and promotes the demonstration of PCC behaviour [113]. However, only *acting* patient-centred (see "PCC activities" in the model of Scholl et al. [15]) without inherently believing in or holding PCC *attitudes* (see "PCC principles" in the model of Scholl et al. [15]) does not mean that HCPs or organisations *are* patient-centred, although PCC actions might still be progress [113]. Consequently, both lines of argumentation, the deontological and the consequentialist, should be conveyed in the development and implementation of PCC, and both aspects, attitudes and behaviours, should be addressed.

In general, PCC has found its way to the overall stated goals for healthcare in most industrialised countries, but its implementation in healthcare (systems) remains challenging and fragmentary. In Europe, several bottom-up efforts were found to improve care for people with multimorbidity using PCC elements, but especially goal setting, personalised care plans and involvement of relatives were not applied [116]. Moreover, the main goals often focus on care coordination and multidisciplinary collaboration, mostly within one healthcare sector. In contrast, approaches to reform healthcare relationships, to involve informal carers or collaborate with organisations outside the healthcare system, remain mostly unconsidered [116].

In Germany, pressure is increasing to provide PCC. Already in 2001 and 2003, the Expert Council on the Assessment of Development in the Healthcare System (Sachverständigenrat zur Begutachtung der Entwicklung des Gesundheitswesens) demanded patient involvement in health system committees and improved patient rights in law [121, 122]. As Brandstetter et al.

argue, patient orientation is now a strong political goal, although it still conflicts with the rigid structures of the healthcare system [123]. By now, PCC and patient involvement are pursued on different levels, mainly on the micro level (patients and physicians) [16]. These strategies are yet not aligned or integrated into the structures of the healthcare system, and no national-level structural incentives exist [16, 124]. While patients themselves think almost every dimension of PCC is relevant, they find them only moderately implemented [18]. Although activities to develop and implement PCC have been remarkably intensified in recent years, and especially patient involvement in decisions has been fostered since 2013 with the patients' rights law, implementation of, e.g., SDM as an important component of PCC remains incomplete on the micro level and is insufficiently promoted by the healthcare system's structures and the healthcare organisations' cultures [17].

Taken together, it becomes apparent that to encounter the challenges of demographic change and especially to meet the needs of the oldest population, PCC is a promising concept. Hence, patients should be put at the centre of all efforts to design healthcare interventions and improvements, and their views should already be involved in the development of care models. So far, however, especially older people have not been included in the development of care models for them, so an important perspective is missing. This leads to this dissertation's primary aim to investigate what matters to people aged 80 and over regarding ambulatory healthcare.

However, as has been described, another important perspective is rarely researched: the views of HCPs providing health services for the oldest. Hence, the next chapter presents how HCPs' views and perceptions of working conditions should be considered.

5. Healthcare professionals providing care for the very old

The requirements of the ageing population previously described are unsatisfactorily met, and reorganisation of the healthcare system has been lacking. In light of this, HCPs in the first line of caring for the oldest are already confronted with these changes and must handle them. For ambulatory HCPs, the workload can already be considered high. For instance, GPs in Germany work 50 to 55 hours per week, while GPs in single-handed and rural practices tend to work more than those in group and urban practices [125]. Work overload and continuous challenging demands can exhaust HCPs, negatively impact how they treat patients and can lead to burnout or the decision to leave their profession [126-128]. In their work, HCPs are frequently exposed to emotionally demanding situations involving patients' or their relatives' fears, suffering or death [128]. Hence, also considering a limited number of HCPs, healthcare appropriate for the ageing population and the very old must consider HCPs' working capacities and job well-being. In the following, the *job demands – resources model* (JDRM) is introduced to conceptualise this.

As Bakker and Demerouti, the developers of the JDRM, describe, job demands such as high work pressure or emotional demands may negatively impact health and well-being, while job resources such as autonomy and social support may have a positive impact [129]. Drawing on criticism of other models of employee well-being, they proposed the JDRM based on the assumption that irrespective of specific job characteristics and risk factors, two categories generally build an overarching model to examine job factors: *job demands* and *job resources* (Figure 2) [129]. Job demands are defined as characteristics of a job that demand ongoing efforts and are consequently associated with certain physiological and psychological costs. They are not necessarily negative but have the potential to become job stressors [129].

By contrast, "job resources refer to those physical, psychological, social, or organizational aspects of the job that are either/or:

- functional in achieving work goals.
- reduce job demands and the associated physiological and psychological costs.
- stimulate personal growth, learning, and development" [129, p. 312].

While job resources are needed to encounter job demands, they also have their value and rights [129]. Bakker and Demerouti further explain two underlying processes resulting in *job strain* or *motivation*. The first process is the path of health impairment, in which certain job characteristics or constant demands lead to exhaustion, also due to compensatory strategies that themselves deplete energy. The second process is the motivational path pointing to job resources' motivational effect and resulting in high work engagement and performance. They can either be motivational by, e.g., supporting personal growth, or they can help in reaching job-related goals [129].

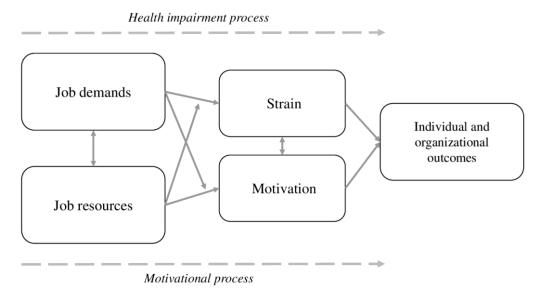


Figure 2: The job demands – resources model (own illustration based on [129, 130])

Moreover, the authors suggest that job resources can buffer the negative impacts of the demands, particularly when these are high [129, 130]. Evidence from empirical studies supports both the assumption of the two processes and the buffering effect of resources [129, 130]. Moreover, reciprocal relationships between well-being as an outcome and job resources and demands were found; hence, stress and motivation can be predictors of more or less favourable working conditions [129, 130]. Consequently, Bakker and Demerouti incorporated the mechanism of *job crafting* in their later model [129, 130]. Overall, while originally developed as a model to explain job burnout, the JDRM is now well-researched and has been widely applied to inform about and research employees' well-being [130].

To date, no studies have investigated particular job demands and resources of HCPs related to working with community-dwelling people aged 80 and over, but some studies have investigated the perspectives of nurses, medical trainees, GPs and dentists in general on older or care-dependent adults, so they are informative on this matter [26, 27, 131-136]. For instance, in a meta-synthesis of qualitative studies on home care for older adults, Olsen et al. developed the core theme of home healthcare providers *being a balance artist* based on the often conflicting needs of their clients and organisational demands [134]. Although PCC was described as the ideal care model for home care clients, it was found that current care was task-oriented, and these conflictual situations were stressful for the providers. This was described as resulting in feelings of exhaustion and guilt [134]. Regarding dental care professionals, Smith and Thomson found in a study in New Zealand on dependent older adults that disability, lack of knowledge of oral health services and self-ageism were challenging patient factors, as were home care facility factors such as lacking skill and knowledge of home care staff regarding oral health impeding their work [135].

In conclusion, the potential exists for further investigating HCPs' perceptions of working with the oldest to better understand what influences their job satisfaction and well-being and how their perceptions might influence the actual provision of health services to older people.

6. Objectives and methods

To address the outlined gaps in understanding ambulatory healthcare for the very old and develop approaches for change, the overall research question for this dissertation was: What matters in developing patient-centred ambulatory healthcare for people aged 80 and over?

The dissertation was based on three dissertation projects (DPs) that investigated the perspectives of community-dwelling people aged 80 and over (DP1, DP2) and of the HCPs' caring for them (DP3). Regarding the explorative and understanding-seeking nature of the research question, an overall inductive, qualitative research design was chosen. The single DPs were developed sequentially, each based on the earlier findings, to achieve the necessary breadth and depth to understand the topic. In the following, the methodological approaches used in the DPs are summarised. An overview is presented in Table 2.

Table 2: Methodological overview of the dissertation projects

DP	Objective	Data collection	Data analysis
DP1.1 [137]	To synthesise qualitative studies on the perspectives of community-dwelling people aged 80 and over regarding ambulatory healthcare	Systematic review of qualitative studies; search conducted in electronic databases, additional electronic and hand searches, forward and backward citation tracking; inclusion of studies from all countries	Thematic synthesis of the included primary studies' findings [138]
DP1.2 [139]	To systematically summarise the specific preferences of community-dwelling people aged 80 and over regarding ambulatory healthcare (from studies identified in DP1.1)	See DP1.1	Meta-summary [140], systematic appraisal of confidence in the evidence using GRADE CERQual [141]
DP2 [142]	To explore what matters to community-dwelling people aged 80 and over regarding general ambulatory health and oral healthcare (not restricted to aged-care settings) in Germany	Qualitative interviews using a semi-structured interview guide	Thematic analysis using inductive and deductive approaches [143, 144]
DP3 [145]	To explore the perceptions and practical reality of physicians and dentists working with people aged 80 and over in ambulatory health and oral healthcare	Qualitative survey; online mode	Structuring qualitative content analysis [146, 147]

In **DP1**, the objective was to systematically elaborate and synthesise the evidence generated so far to understand older people's perspectives regarding ambulatory healthcare. In **DP1.1** [137], following the research question "What matters to people aged 80 and over regarding ambulatory healthcare?", qualitative studies covering older people's experiences, needs, preferences and expectations were systematically searched in electronic bibliographic databases. This was complemented by searches in Google Scholar and forward and backward citation tracking of eligible studies [137]. The retrieved results were assessed for eligibility through title and abstract screening and full-text screening. Included studies were appraised regarding their quality using the *Quality Appraisal Checklist for Qualitative Studies* of the National Institute for Health and Care Excellence (NICE) [148] to evaluate the synthesised findings' solidity [137]. From the included studies' research reports, all parts describing findings were extracted and thematically synthesised [137]. Thematic synthesis is an approach used for qualitative meta-synthesis that aims at developing an integrated representation and explanation of the primary studies' findings [138, 140, 149]. The synthesis comprised line-byline coding of the extracted material, followed by the development of descriptive themes and analytical themes [137, 138].

DP1.2 [139] was a secondary analysis based on the studies identified in DP1.1. While the thematic synthesis provided three analytical themes that explained older people's views expressed in the primary studies' findings, it was found that an overview of these descriptions would also be of practical relevance. Therefore, following the research question "What are the specific preferences and wishes of older people regarding favourable aspects of ambulatory healthcare?", the studies included in DP1.1 were meta-summarised [139, 140]. The extracted studies' findings were first coded line-by-line, then clustered around different healthcare aspects and condensed into specific statements on the desirability of ambulatory healthcare features [139]. Afterwards, these statements were systematically appraised regarding the confidence in their evidence using GRADE CERQual, a tool that was specifically designed for qualitative evidence syntheses [141]. With CERQual, each review finding (the statements developed from the meta-summary) was appraised regarding 1) methodological limitations, 2) coherence, 3) data adequacy, and 4) data relevance, resulting in a qualitative evidence profile disclosing either high, moderate, low or very low confidence for all statements [139, 141].

Drawing on the results and research gaps identified from the systematic review in DP1, a qualitative interview study was conducted in **DP2** [142]. To answer the research question "What matters to older people regarding ambulatory health and oral healthcare?", qualitative interviews were conducted in and around Cologne, Germany. This study aimed at 1) investigating the results from DP1 further, especially in the German healthcare context and 2) exploring older people's views of the previously neglected area of oral health and healthcare [142]. Community-dwelling people aged 80 and over were purposefully recruited [150] for interviews on their previous experiences and perceptions of good healthcare regarding either general/specialist ambulatory healthcare or oral healthcare. The interviews were conducted using a semi-structured interview guide and afterwards transcribed verbatim [142]. The results

were analysed thematically [143, 144], facilitated by an inductively developed codebook incorporating the results from DP1 [137].

Based on the findings from DP1 and DP2 focusing on older people, **DP3** [145] followed the research question "What are the views and perspectives of physicians and dentists on caring for people aged 80 and over in ambulatory health and dental care?". DP3 aimed to describe and understand occupational routines and views on caring for older people and physicians' and dentists' perceptions of good ambulatory healthcare for them [145]. Therefore, a qualitative online survey [151] was conducted, in which physicians and dentists practising in North-Rhine Westphalia, Germany, could participate. Qualitative surveys mainly pose open questions to explore participants' subjective experiences and views and serve a qualitative research logic [151]. The survey was pretested iteratively in three rounds before it was provided with an online link via supporting physicians' and dentists' networks and associations [145]. The results were analysed following Kuckartz's approach of structuring qualitative content analysis [146, 147] to develop a descriptive codebook by 1) deriving main categories from the open-ended survey items, 2) coding the survey results with the broader main categories, and 3) inductively coding the material in the main categories to develop more precise subcategories. After this descriptive procedure, the coded survey data were explored for mutual patterns and compared between the groups of physicians and dentists [145].

7. Publications and results

In the following, the four publications resulting from the three DPs as the core of this dissertation are listed and their results are briefly summarised. The complete publications are available in the appendix.

1. What matters to people aged 80 and over regarding ambulatory care? A systematic review and meta-synthesis of qualitative studies

Angélique Herrler, Helena Kukla, Vera Vennedey, Stephanie Stock. *European Journal of Ageing* 19, 325–339 (2022). https://doi.org/10.1007/s10433-021-00633-7

Two-year journal impact factor at the time of publication: 2.711

The first publication resulted from DP1.1. In total, n = 22 qualitative studies were included, comprising 330 older people and conducted mainly in Northern and Western Europe [137]. The analytical integration of the 22 studies' single findings yielded three core motives that represent older people's underlying wishes regarding ambulatory healthcare, explaining their specific views, preferences and evaluation of experiences as described in the single studies.

The first core motive was *feeling safe*. Concerning existing or possible future deteriorations in health and abilities, older people strongly wished to be made to feel safe. For instance, they valued individually tailored support and a continuous point of contact, wanted to gain sufficient information on their care options and medications, and valued long-term and trustful relationships with their HCPs [137].

The second core motive, *feeling like a meaningful human being*, was related to older people's self-perceptions and external perceptions [137]. This finding revealed the fundamental wish of not being viewed as deficient despite limitations in (functional) health. Hence, important manifestations of this motive regarding ambulatory healthcare were the wish of being treated friendly and experiencing meaningful social contact through being granted attention and conversation [137].

The third core motive identified was *maintaining control and independence*. It was found that older people made several different adaptations in their lives when their physical or cognitive functions started to decline. However, being as autonomous as possible was extremely important to them. Consequently, they expected healthcare to recognise this need, identify what is still possible and meaningful to them, and support this wish by providing the right scope of support. This also included involving older people in their healthcare and decisions whenever possible, sensitively balancing the chances and risks of receiving support concerning the maintenance of control and independence [137].

2. Which features of ambulatory healthcare are preferred by people aged 80 and over? Findings from a systematic review of qualitative studies and appraisal of confidence using GRADE-CERQual

Angélique Herrler, Helena Kukla, Vera Vennedey, Stephanie Stock. *BMC Geriatrics* 22, 428 (2022). https://doi.org/10.1186/s12877-022-03006-6

Two-year journal impact factor at the time of publication: 3.921

The second publication resulted from DP1.2. Building on the results of DP1.1, a meta-summary and appraisal of confidence in the evidence with GRADE CERQual were performed. A total of 23 review findings representing preferable attributes of ambulatory healthcare from the perspective of people aged 80 and over were identified, of which 14 findings resulted in a high appraisal of confidence, five findings were assigned a moderate appraisal of confidence and four resulted in a low appraisal of confidence [139].

These specific preferable features of ambulatory healthcare revealed that besides healthcare structures, aspects of relationships with healthcare providers were found to be especially important and well supported by the empirical studies conducted so far. Findings in the "low confidence" section tended to be based on a smaller number of studies and more contrary individual study findings. This could be a hint at a less generalisable feature, with a greater need to negotiate it in individual care situations [139].

3. Characteristics of desirable ambulatory health and oral healthcare from the perspective of community-dwelling people aged 80 and over $-\mathbf{A}$ qualitative examination

Angélique Herrler, Helena Kukla, Anna Greta Barbe, Vera Vennedey, Stephanie Stock. *Age and Ageing* 51(11): afac258 (2022). https://doi.org/10.1093/ageing/afac258

Two-year journal impact factor at the time of publication: 12.782

The third publication resulted from DP2, in which n = 22 community-dwelling people aged 80 and over participated in interviews between October 2020 and July 2021. Sixteen aspects relevant to desirable ambulatory health and oral healthcare were elicited in four areas: attributes of health and oral healthcare providers, patient-provider interaction, the output of health and oral healthcare, and the organisation and context of health and oral healthcare. Three aspects were newly identified compared to the prior systematic review: the result of healthcare, costs, and practice characteristics [142].

Moreover, it was found that although older people value similar attributes of healthcare and oral healthcare, the practical meaning of the characteristics identified could differ. For example, HCPs' competence was understood as thoroughness and good communication in healthcare, while competence in dental care was more strongly referred to as medical-technical skills [142]. However, good communication, relationship-building and information exchange were generally important to the participants. Overall, it was striking how older people were often

aware of possible deteriorations in functional health and abilities, but rarely regarding their oral health, although they described it as relevant for important aspects such as eating or appearance [142]. It was also noticeable that the participants seemed to have internalised a negative stereotype of older people unnecessarily using healthcare resources and their urge to clarify that they were different [142].

4. Providing ambulatory healthcare for people aged 80 and over: Views and perspectives of physicians and dentists from a qualitative survey

Angélique Herrler, Lisa Valerius, Anna Greta Barbe, Vera Vennedey, Stephanie Stock. *PLoS ONE* 17(8): e0272866 (2022). https://doi.org/10.1371/journal.pone.0272866

Two-year journal impact factor at the time of publication: 3.752

The fourth publication resulted from DP3. A total of n = 87 HCPs participated in the qualitative survey, from which 77 cases were included in the structuring qualitative content analysis [145]. Both physicians and dentists characterised providing care for older people as challenging. This was due to the older patients' usually more complex health conditions such as multimorbidity and limitations such as hearing impairments that could influence communication. Overall, the treatment flow common with younger patients did not work with older people, and this seemed to put particular stress on the HCPs [145]. While they shared the ideal of providing individual, patient-centred care for older people, they described this as more difficult or impossible due to the consisting structures of the healthcare system limiting their available time for patients, especially because of fragmentation and deficient reimbursement. Hence, apart from patient aspects, structural elements of the healthcare system such as reimbursement were considered the main points facilitating or hindering good healthcare for older people [145].

In directly interacting with patients, especially physicians noticeably reported a lack of patient compliance as a barrier to providing the care they perceived as suitable. Moreover, dentists complained about a significant lack of awareness among older patients and physicians or other healthcare professionals regarding oral health and care and demanded an integration of oral healthcare into holistic healthcare concepts [145].

8. Discussion of results

This dissertation aimed to investigate the perspectives of people aged 80 and over, and of HCPs, to understand what matters in the development of patient-centred ambulatory healthcare for the very old. Different qualitative empirical approaches were used to describe and analyse the views, experiences, and priorities of both groups comprehensively as well as in-depth.

DP1 delivered the first comprehensive approach to synthesise qualitative studies exclusively for the group of community-dwelling people aged 80 and over. This is important since this population group is growing fast, with considerable changes in health and challenges occurring around the age of 80 years (see Chapter 2), but many empirical studies only broadly summarise older people in the age group 60+ or 65+ [4, 62]. As a result, DP1 delivered important descriptive and explanatory insights exclusive to this age group [137, 139]. The systematic review revealed that studies so far had mainly been conducted in aged-care settings such as home care, and the participants of the included studies predominantly showed or were chosen because of considerable health limitations such as frailty or pre-frailty [137, 139]. Moreover, no study in the German healthcare context and no study investigating oral healthcare could be found. Therefore, DP2 expanded and consolidated the results from DP1 by conducting the first community-based interview study with people aged 80 and over without inclusion or exclusion criteria regarding health status in Germany, explicitly incorporating the area of oral healthcare. DP3 extended these advances with the perspectives of HCPs. Taken together, the three DPs can inform the appropriate design of healthcare models for the oldest old and facilitate the understanding of what is relevant in healthcare for both older patients and HCPs.

In the following, a joint summary of what constitutes patient-centred ambulatory healthcare for the very old is provided, based on the dissertation projects' results. Figure 3 provides an overview of the combined main results from the DPs. The results are further discussed in three areas: 1) understanding of health and well-being and the role of ambulatory healthcare in old age, 2) interactions between HCPs and very old people, and 3) providing healthcare for people aged 80 and over as a challenging task for HCPs. In this chapter, the results are discussed with a particular focus on contextualisation with other studies and links to theoretical approaches, while Chapter 9 discusses the implications for research and practice arising from that.

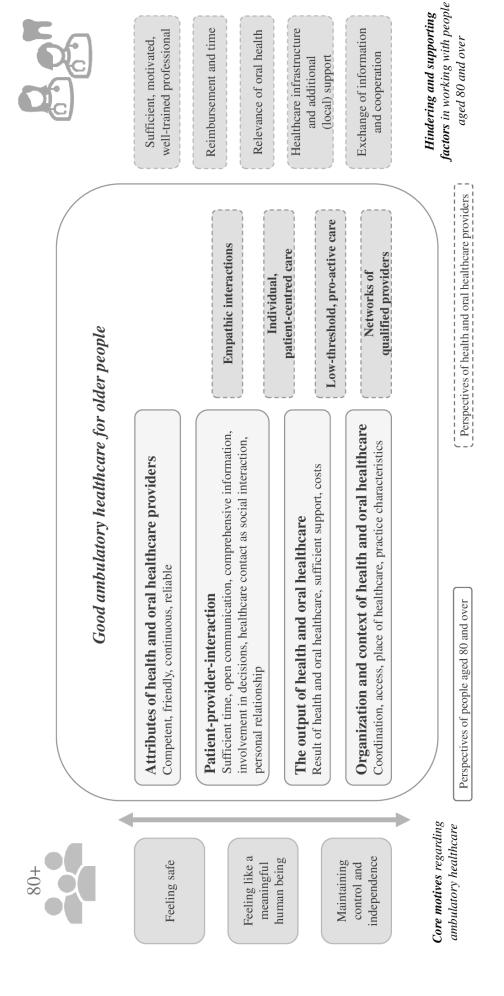


Figure 3: Patient-centred ambulatory healthcare for the very old: Overview of combined results

8.1 Patient-centred ambulatory healthcare for the very old

From the perspective of people aged 80 and over, four areas are relevant to the perception of receiving good healthcare. Friendliness, competence, continuity and reliability are important attributes of health and oral healthcare providers. While the older people addressed these comprehensively, HCPs discussed attributes such as respectfulness and empathy as part of an empathic interaction style with patients [137, 139, 142, 145]. Both parties emphasised the importance of good communication to exchange all necessary information and to agree on the best possible treatment, and help patients feel safe and valued. The necessity of having enough time for that was agreed on [137, 139, 142, 145].

The people aged 80 and over broadened the aspect of communication and wished for *patient-provider interaction* that included comprehensive information, open communication and involvement in decisions and care. Moreover, from the perspective of older people, the foundation is building a personal relationship and viewing healthcare interaction as a social interaction [137, 139, 142].

Relevant aspects of the *output of health and oral healthcare* are the result of healthcare, sufficient support and costs. Both parties referred to the patient's individual needs as a central component of care [137, 139, 142, 145]. HCPs also already referred to PCC and narrative medicine as keywords [145]. Older people wanted to be ensured that their needs would be met sufficiently, while HCPs frequently explained how disease-based guidelines are not useful and that *individual care* plans need to be made with a focus on maintaining functionalities and hence, independence [137, 139, 142, 145]. While they pointed to the role of good counselling, older people considered good communication and interaction as parts of a desirable result of healthcare [137, 139, 142]. What is seen as sufficient or "right" support and care was highly individual but could, for instance, incorporate thorough examinations, follow-up appointments, comprehensive explanations of treatments or specialist referrals [142]. Hence, thoroughness and communication are not only a tool for producing good healthcare results: In raising the feeling of being heard, seen holistically and taken seriously, these aspects are themselves desirable results of healthcare [137, 142, 152].

In the *organisation and context of health and oral healthcare*, healthcare coordination, access to health services, the place of care and practice characteristics are important aspects [137, 139, 142, 145]. For older people, whether their perception of urgency was taken seriously was mirrored in fast and uncomplicated access [137, 142]. HCPs also wanted to *provide low-threshold, proactive care*, including a seamless flow of information and the reassurance that their patients receive any support they need, for example, regarding medication intake [145]. Independent of individual needs, older people's dominant wish was to have continuous, easily accessible contact persons who could react to them in the case of an acute emergency and in minor cases such as queries regarding medication intake [137, 139, 142]. Telephone contact for that was often suggested as sufficient. Hence, implementing broad telephone availability of a practice or practice network could already be an appropriate measure to ensure older people

feel safe (because they reach help fast), meaningful (because they are heard and not ignored) and autonomous (because they can independently realise advice without great effort).

Although acceptance of delegation was found to be based on low evidence in DP1.2 [139], it was apparent in all studies that under certain conditions such as continuity of the contact person(s) and for certain tasks, another HCP would be accepted in this place [137, 139, 142]. HCPs also explained that local and social structures and *qualified staff and provider networks* [145] were required to provide good care. Consequently, drawing on both parties' ideas, professional roles and duties and how to connect relevant stakeholders must be considered.

Concerning these results, what constitutes good ambulatory healthcare in older age and the concept of PCC as presented by Scholl et al. [15] and Zeh et al. [18] are greatly similar. Hence, it can be concluded that PCC generally fits older people's and HCPs' ideas of good healthcare in older age. This is an important finding since the conceptual closeness and often overlapping description of *good healthcare* and *patient-centred care* have been criticised [153]. The results from DP1-DP3 indicate that this might not be due to vague conceptualisations. Seemingly, what patients and providers currently consider to be high-quality healthcare *is* PCC. In Chapter 9.2, conclusions for the further development of care models are discussed. While the conceptual frame of PCC was described similarly [15, 18], the detailed results described in the publications from DP1-DP3 are beyond that suitable to understand the specific interpretation and practical meaning of the concepts' aspects in the context of ambulatory healthcare for the very old.

Moreover, the results showed that HCPs most often referred to healthcare structures [145], while older people referred to relationships [137, 139, 142]. This reveals a considerable gap in the representation of what matters to patients in the currently existing care models, which also focus much more strongly on healthcare structures, and improvement of relationship-building, apart from SDM, is rarely considered (see Chapter 3). In DP3, HCPs seemed to expect better patient-provider interactions and relationships if only the structures were improved [145]. However, since most care models in the past 30 years tried to improve structures without equally considering relationships, and those still being worthy of improvement from the older people's perspective, this could be a wrong conclusion. This is especially important against the background of older people's core motives in healthcare identified and explored in DP1, whose fulfilment is particularly dependent on good healthcare relationships [137]. In a qualitative study of primary and secondary providers of acute care for older people in the Netherlands, Brouwers et al. found results quite similar to this dissertation's, that among HCPs "only two respondents [...] mentioned the social aspect as a very important aspect in the care process" [154, p. 338]. The authors further described that HCPs' improvement suggestions mainly focused on technical processes such as referrals and consultations or interdisciplinary cooperation to enhance efficiency and quality [154]. The implications of a stronger focus on relationship-building versus healthcare structures are discussed further in Chapter 9.2.

8.2 Understanding health, well-being and the role of ambulatory healthcare in older age

Apart from describing ambulatory healthcare as suitable for the very old, the dissertation explored underlying motives and perceptions of older people and HCPs that form their views and behaviours. One important part of that was the development of older people's core motives regarding ambulatory healthcare. Moreover, older people's and HCPs' overall ideas of health and the duties of ambulatory healthcare in old age play an important role.

8.2.1 Older people's core motives regarding ambulatory healthcare

In DP1, three core motives regarding ambulatory healthcare were developed from empirical studies: feeling safe, feeling like a meaningful human being, and maintaining control and independence [137]. These were found to cover a broad range of care contexts and health conditions and were confirmed in DP2 [137, 139, 142]. These fundamental wishes were found to interact and complement each other rather than being hierarchically structured, and several ways (i.e., specific measures or care elements such as SDM) could be appropriate to serve older people as long as they consider their basic needs [137, 139, 142]. Experiencing the opposite of preferred attributes, e.g., being given the feeling of being inferior or unimportant, could negatively influence the perception of the core motives [137]. Hence, the practical implementation of ambulatory healthcare elements feeds into a continuum of feeling more or less safe, meaningful, and autonomous (Figure 4). Two theories from different contexts propose similar elements to these core motives: Abraham Maslow's theory of human motivation and Aaron Antonovsky's salutogenesis.

Maslow's theory of human motivation is grounded on the idea of humans generally having basic physiological, safety, belongingness/love and esteem needs, followed by the need to know and understand, aesthetic needs and finally, the need for self-actualisation and transcendence [155-157]. The fulfilment of all these needs means having a good life, being happy and experiencing well-being [155, 157]. The needs described by Maslow were often interpreted as hierarchical and their representation as a pyramid became popular, claiming that after the fulfilment of one need, one "goes up" to the next. Especially for this hierarchical order and difficult testability, Maslow's theory earned much criticism [155, 158, 159]. However, this might be a misconception of what he meant since, for instance, Maslow himself did not introduce the representation in form of a pyramid, and several modern interpretations rather tend to differentiate between deficiency needs and growth needs [159, 160]. Moreover, the needs do not necessarily appear one after another after fulfilment, but certain needs can at times be dominant, especially during certain life or age phases [159, 160]. Winston argues that the order of need dominance follows the life course: basic and safety needs in younger years, belonging and self-esteem in middle years, contribution and generativity in adulthood and older age [159]. In the context of this dissertation's results, this could be a parallel or alternative manifestation of developmental life tasks and the wishes older people have and what they need from healthcare to master them. However, the three core motives had no explicit structure, and they were equally important [137]. But it is possible that one motive, such as feeling safe, becomes more important in certain situations such as an acute exacerbation of a health condition [137]. Therefore, specific preferred features as described in DP1 or DP2, such as receiving fast access and help, dominate others in these situations, and other motives and preferences such as SDM may become less important [139, 142]. What can, however, be learned from this dissertation's results in comparison with Maslow's theory is that despite physical limitations occurring in older age and a certain focus on their compensation, older people clearly show a *growth orientation* regarding their life, including their health, while also accepting that their body ages. Hence, they are trying to find growth in the "deficit".

Another theoretical concept in line with the identified core motives is the sense of coherence (SOC) as an important component of salutogenesis. The salutogenic model, originally introduced by Aaron Antonovsky in 1979, focuses on the origins of health in contrast to the origins of disease [161]. Antonovsky developed the salutogenic orientation to understand which positive aspects and inputs support individuals in environments in which several different stressors cannot be avoided, instead of controlling the numerous single risk factors facilitating or causing specific diseases [162]. Salutogenesis, as Antonovsky postulated, "leads us to focus on the overall problem of active adaptation to an inevitably stressor-rich environment" [163, p. 9]. He proposed refuting the idea of distinct states of health or illness and instead considering it a continuum of being rather healthy (health-ease) or rather ill (dis-ease) [164, 165]. In the idea of salutogenesis, protective factors and risk factors influence how people move on this continuum. In contrast to risk factor models of health and disease, salutogenesis especially focuses on the protective factors that keep people healthy [164, 165]. Antonovsky found the core of salutogenesis to be the SOC:

The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments on the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement [163, p. 19].

Hence, the elements of the SOC are 1) comprehensibility, 2) manageability, and 3) meaningfulness [162]. The SOC is a representation of how a person views life and its challenges [166]. The core motives identified in DP1 [137] have a strong similarity with the SOC, although particularly developed in the healthcare context. It could be assumed that SOC is an inherent part or driver of older people's core motives regarding healthcare that explains their specific preferences and respective behaviours [137, 139, 142].

Since this dissertation inductively identified the core motives, it cannot be considered a test of Maslow's or Antonovsky's theory. However, in discussing their features and similarities, it becomes apparent that older people, and humans in general, are growth-oriented in their lives, health and well-being, and this orientation has implications for their perceptions and wishes regarding ambulatory healthcare. Especially the ideas of health as a continuum from

salutogenesis and the varying dominance of certain needs from Maslow's theory enhance the conceptualisation of older people's core motives in the context of patient-centred ambulatory healthcare (see Figure 3). It also clarifies that needs regarding healthcare cannot be considered separately from general needs in life, which is important for what can or should be expected from healthcare.

8.2.2 Perceptions of health, age and the role of healthcare in older age

While the core motives discussed explain the reasons for expressing specific wishes, preferences and beliefs regarding healthcare, how this results in older people's (and HCPs') beliefs, behaviours and interactions needs to be considered further.

As described in Chapter 2, the age of 80 currently constitutes a threshold regarding the burden of morbidity overall, despite individual heterogeneous ageing and health trajectories. It presented, for instance, how the model of selective optimisation and compensation proposed by Baltes and Baltes [65] explains how older people manage their lives to maintain well-being. This was also reflected in the results from DP1 and DP2, which found that older people emphasised their activities and that they valued advice for daily life and activation [137, 139, 142]. This is an expression of how older people focused on meaningful options for activities and discovered new ones such as senior citizens' sports or gardening [142]. Hence, they want to be recognised for their activities, also in light of their life's work and wanted to be respected and seen as meaningful societal contributors [137, 142]. Recognising and supporting these individual achievements and goals is closely linked to the core motive of feeling like a meaningful human being [137]. It is also relevant to maintain control and independence since this is a balancing act of not receiving too much but the right and sufficient support to live life as one wishes, and to avoid the need of further care and support [137]. This is also reflected in older people's wishes to receive more preventive measures and routine examinations that ensure them that everything "works well" and will not deteriorate soon and to give them control over possible counteracting measures [137, 139, 142].

In the German context, older people in DP2 often found it unjust that preventive and routine examinations were limited by the SHI, also within certain age ranges, and people being privately insured or being able to pay out of pocket would therefore receive better healthcare [142]. HCPs in DP3 also referred to the strong role and relevance of prevention to enable a good life for their patients, but they often argued that prevention has to be started *early* in life, potentially implying old age is too late [145]. Most emphasised the importance of individual goal setting and care planning, including routine follow-ups, especially for a range of chronic conditions to ensure independence, mobility and safety [145]. Overall, it seems that HCPs still have a clear focus on *what is wrong* with their older patients' health, as is especially visible in their characterisation of them as physically and cognitively impaired, medically complex and challenging [145]. Some HCPs also expressed being annoyed by older people's unrealistic or inappropriate goals and their "stubbornness" if they insisted on pursuing them [145].

On this matter, the dissertation's results point to two important issues: Firstly, HCPs showed a rather deficit-oriented and negative view of older people [145]. Secondly, conflicting with their otherwise striving for a positive and health-oriented view, older people themselves showed internalised negative stereotypes about the old [142]. Several participants described that older people might unnecessarily "block" healthcare resources and the limited valuable time physicians have for their patients. They needed to differentiate themselves from *those* older people and to emphasise they would only seek help if truly necessary [142].

Such ageist stereotypes are quite powerful; they can influence how and whether older people seek help, follow prevention measures, or are convinced of their control regarding their health, how they perceive their lives, their experience of well-being, and ultimately, their overall health [167-170]. Ageist stereotypes influence, on the one hand, older people and their beliefs and on the other hand, how other people, such as HCPs, perceive them and interact with them. In a comprehensive analysis of an English 600-million-word corpus from 1810-2019 comprising newspapers, magazines and fictional and non-fictional books, Ng and Chow investigated the development of ageing narratives [171]. Since literature and media certainly reflect societal images, their findings were striking: Over the past 210 years, ageing narratives were found to steadily become more negative. Older people were increasingly ascribed a lower status, less warmth and less competence. At the same time, descriptions of ageing became more medicalised and connected to "dark" themes such as illness, disability, and death and they were increasingly described as vulnerable and in need of social welfare [171]. This was also apparent in the results of this dissertation [137, 142, 145]. Apart from the increasing average life expectancy, Ng and Chow explain their results with the important societal vent of industrialisation, which turned a hitherto positive image of older people to a negative one due to the focus on fast work and efficiency and the uselessness of older people due to declining physical capacities [171]. Moreover, older people are often generalised as a homogenous group, despite the considerable heterogeneity of their lives [171]. This was also partly apparent in DP3, where only a few HCPs pointed to older people's heterogeneity in characterising them [145].

This image of old age is a harsh contrast to older people's self-perceptions and denies their persisting potential and wishes to pursue a meaningful life. As described in Chapter 2, old age is a life phase in which new goals are selected and other goals need to be left behind [62]. However, society might have ideas of age-appropriate goals and base their support on whether older people choose the "right" ones [62, 172]. Hence, if societal conceptions of older age are deficit-oriented, they might withhold resources for older people to design their goals and lives in a more growth-oriented way. If older people internalise these stereotypes, they might not even perceive this as wrong, but they will experience a mismatch between their own and perceived images of their life as insulting [169]. This dissertation's results showed intra- and interindividual differences. On the one hand, the urge to differentiate oneself from older people overusing healthcare indicates that one is in line with the "right" goals and behaviours from a societal perspective [142]. On the other hand, in several examples, older people felt sad or insulted by how they were deprived of healthcare and attention due to their age [137, 139, 142].

Other studies confirm how a focus on diseases promotes a deficit-oriented view among HCPs if not counteracted. In two systematic reviews on nurses' and student nurses' attitudes regarding older people, it was found they had light to moderate positive views, but also several negative attitudes: Older people were often stereotyped as incapable of decision-making, hence less involved, and seen as a burden due to their higher demands of attention and care complexity [26, 131]. Negative perceptions of older people often referred to the higher burden of caring for them, unambiguous health conditions and treatment plans, and distressing outcomes such as death [26, 131, 132].

Taken together, these findings make it apparent that people aged 80 and over face and struggle with medicalisation and illness-reduction of their lives. This recalls Parsons' description of the role of the ill person, who has rights and duties and exchanges autonomy over their state with responsibility. Here, being ill poses a phase of deviance from the normal, healthy state [173]. This dichotomy, though, does not fit the older age that is a life phase, and while most older people have several (chronic) conditions, this does not mean they cannot be or do not feel healthy. Hence, the healthcare system, being designed primarily for limited phases of illness, still serves the role of ill persons but not beyond that. Against the background of the theoretical approaches introduced in Chapter 2, several examples from DP1 and DP2 confirm how older people reorganise and follow new goals and strategies to achieve well-being and satisfaction and how healthcare impacts how they perceive being supported or enabled to do so [137, 139, 142]. It could be argued that focusing on prevention and health (in contrast to disease) is a *strategy to handle* current health status and possible deteriorations and that denying or complicating access to preventive measures means older people are *hindered* in that.

On this matter, the DPs also produced results on older people's and HCPs' perceptions of their interactions, particularly regarding communication, SDM and the building of care relationships, which are discussed in the following.

8.3 Interactions between older people and healthcare providers

In all DPs, the role of good and valuable care relationships was dominant [137, 139, 142]. This was particularly apparent in the numerous review findings regarding social interaction in the healthcare context with a high rating of confidence in the evidence in DP1 [139]. What is interesting regarding the more specific aspect of SDM is that in the systematic review and the interview study, participants wished to be comprehensively informed and equally involved in care and decisions, while a minority of people stated they would like to leave the decision with the professional [137, 139, 142]. This is striking because it is frequently suggested that older people, in contrast to younger generations, prefer a paternalistic model of healthcare and decision-making [112, 174, 175]. In light of this dissertation's results, this is an astonishing misconception. Although specific preferences regarding decision-making style and mode of information differ, being informed and discussing their health and care is generally important to all older people. This can be seen in their strong wishes to be taken seriously with their

matters, to receive thorough explanations, to be able to speak without being interrupted, and to have a trustful, confidential atmosphere in which concerns and questions can be brought up uninhibitedly [137, 139, 142]. Hence, although someone competent (the HCP) making the final decision might be preferred by some or might be necessary, this does not mean older people do not want to be part of the prior decision-making *process*, which comprises a broad interaction of mutual information sharing. However, if

- more than one option is not made explicit,
- not enough time is granted to speak about all meaningful aspects,
- older people have the feeling of "stealing time" or being signalled their need to discuss is undesired.

their confidence and possibilities of getting involved may decrease.

Individually perceived abilities seem to play an important role in this matter. For example, other studies found that lower levels of health literacy influence decision-making preferences and that health literacy may especially influence personal motivation to seek information, resulting in passive behaviour [176]. Parallel to that, it was also found that older people tend to have lower health literacy levels than the younger population [177]. Hence, instead of concluding that older people do not want to be involved in decision-making, it could be necessary to focus even more on empowering this group to take part, strengthen their health literacy and decisionmaking abilities, and create the atmosphere they need to discuss their goals and decisions. As Taylor argues, it might not be correct that older people would value PCC or SDM less but that they want to see the options and the "roadmap" while not necessarily wanting to control the whole process or decisions [112]. In a large qualitative study in eleven European countries among over 400 people aged 70 and older on decision-making involvement at the GP, Bastiaens et al. found that preferences for decision-making were ambiguous. Many older people wished to be involved, but some also described that the GP was the expert who should make the decision [178]. However, as in DP1 and DP2, patient-provider relationships, talking, asking questions, being listened to, and receiving information on health status, treatment and prevention possibilities were equally important [178].

Some HCPs in DP3 expressed that older patients would have unrealistic views regarding their health and possible treatment goals, while others, especially dentists, reported perceiving older people as sometimes being in doubt whether a certain treatment "would be worth it anymore" considering their older age [145]. Although communication and involvement in decision-making were often mentioned, especially GPs described their perception that older people were more paternalistically oriented. In several cases, HCPs referred to older people's noncompliance, due to impairments and limitations but also due to supposed stubbornness. Some HCPs explicitly stated that good healthcare would result from patients behaving compliantly [145]. Compliance means a clearly defined idea of what has to be done (mostly identified by an HCP) that is followed by the patient [179]. In light of the diverse health trajectories and non-applicability of standardised treatment concepts [145], this is a striking

statement that is in contrast to older people's expressed wish to discuss individual treatment options [137, 139, 142]. Frequently, HCPs also referred to assumed dementia when their patients refused their treatment plan [145], which was also found in a study by Zwijsen et al. [27]. Such beliefs about older people can result in their stigmatisation, treating them inappropriately and not involving them in decisions [180].

These beliefs and expectations could be an expression of HCPs' professional education and socialisation or general misconceptions about older people. They could also be based on a perceived failure or impossibility because negotiations about care goals and treatment plans with older people break the boundaries of usual routines established in the medical and healthcare system. This is reflected in other studies. For instance, Wrede et al. showed that patient-centred communication is still only moderately practised and that HCPs tend not to initiate discussions of treatment priorities [181]. Another example comes from a big qualitative study with GPs in eleven countries, in which Wetzels et al. revealed that what GPs understood as patient involvement was often reduced to communication [182]. In another study on PCC, Bodegård et al. summarised that

patients who had more than one reason for their visit indicated that they were not listened to without interruption, did not have their questions answered, and were not satisfied to the same extent as those with one reason for their visit. The doctors' responses did not reflect that they perceived any of these differences in these consultations [117, pp. 5-8].

It is interesting that in the last study, the physicians' mode of communication seemed to change if the reason for the visit was more complex, meaning it had more than one specific reason. Assuming that PCC and SDM are modern ideals of healthcare also influenced by general socialisation, not only HCPs but also older people might be used to a certain kind of doctor-patient communication. Even if HCPs, for instance, share the ideal of SDM [145], they might lack the skills or do not habitually stick to that in situations of complex health issues, especially if the time frame is short. The same might be true for older patients; hence, they might not necessarily bring up their wishes or demand that their HCPs discuss goals, especially considering their internalised stereotype of the older person as blocking healthcare resources [142]. Consequently, if neither the HCP nor the patient initiates such discussions, underlying misunderstandings and disagreements, resulting in "noncompliance", are not surprising [112].

This situation also results in important although not necessarily medical or acute topics being cut off from consultations. For instance, it became apparent that older people think about their future health and life trajectories, and they would like to discuss and plan them to feel prepared and safe [137, 139, 142]. A study with older couples not yet receiving professional support in Sweden showed concerning future development and future care preferences, *maintaining the self* and *being cared for with dignity to the end* were important core themes [183]. The fear of not being received and treated as an individual anymore was great [183]. Hence, how life will go on and how to preserve dignity until the end of life are important topics for older people. A systematic review and subsequent interviews by Kukla et al. found that informing oneself about

death and dying, and especially talking about death-related topics, also with HCPs, was important to the participants and helped them experience positive emotions, satisfaction and well-being [152, 184]. Interestingly, the needs and approaches to the two groups of older people and people with a life-limiting disease did not differ [152, 184].

Although the discussion of death might be interpreted as negative and loss-oriented, the results from DP1, DP2, and Kukla et al. show that older people usually do not see it like that. By contrast, they want to actively engage with the topic, they want to understand and plan what comes ahead, and they can receive safety, meaningfulness and well-being through this mastery [137, 139, 142, 152, 184]. Older people wish to discuss such existential, not purely medical questions with HCPs [103, 137, 142, 152, 184, 185]. For HCPs, though, non-medical issues and discussions are an important aspect of their perception of older people being a challenging patient group [145]. While some understand the incorporation of psychosocial and meaning-of-life aspects as an important field of communication with their patients and a source of meaning and value for themselves, several felt they lacked the resources, in particular, time, or competencies to do so properly. They also mentioned that this was not considered an HCP's area of expertise or role [145].

In conclusion, older people wish to build personal relationships, communicate broadly with their HCPs on existential life questions and plans, and wish for SDM. This seems to conflict with certain views and beliefs of HCPs, such as their perceptions of older people, their professional roles or their perceived capabilities. Therefore, the following section discusses the dissertation's results from their perspective.

8.4 Providing healthcare for people aged 80 and over: A challenging task

Several factors in providing healthcare to older people were described as having the potential of being either impeding or supportive from the perspective of HCPs in DP3 [145]. One of the most important factors in providing good healthcare was the patient's health status. Hence, prevention was considered valuable. While physicians especially referred to healthy lifestyles already in younger years, dentists seemed to be more in the present and referred to ongoing possibilities of prevention and prophylaxis [145]. Interacting with the broader local or social environment of the older patient, further stakeholders such as relatives or formal caregivers were especially identified as both possibly complicating and facilitating good care, depending on their interests and whether they acted in line with the provider's and patient's goals and plans [145]. Having sufficient reimbursement and time, proper information exchange with other HCPs, and transport solutions for patients with restricted mobility were further considerable factors [145]. Good interactions with the patient were seen as supportive, but physicians also referred here to patients' potential stubbornness as impeding. By contrast, dentists reported possibly conflicting goals or views on the right treatment but emphasised the patient's final say in what was done [145]. They moreover stated that awareness of the relevance of oral health among other HCPs, patients and their relatives would help in providing good care. Having a good team, proper professional networks, the professionals' motivation and ongoing training were generally described as important and supportive [145].

These findings of the dissertation are in line with other studies on further HCPs or healthcare settings concerning caring for older adults (often defined from 60+ years on), and the challenges accompanying that. In particular, these comprised the patients' complexity, communication challenges, healthcare coordination and fragmented structures, administrative burden and time pressure [27, 133, 134, 154, 186, 187]. Caring for older adults in the current healthcare system is particularly demanding for HCPs. For example, not being able to rely on proven treatments or guidelines can make HCPs feel frustrated since it increases their uncertainty about providing good care for their patients [27, 133, 145].

Taken together, these results show that healthcare that is not designed to care for older people is not only bad for them. It also puts substantial stress on HCPs, who are necessarily confronted with older people's demands in their daily practice, whether they are prepared or not [145]. Against the background of the JDRM (see Chapter 3), the described barriers and challenges can be considered ongoing job demands that can negatively impact HCPs' well-being or make them consider leaving their job in a process of *job strain* [129, 130]. Their perceptions of their working environment (and hence of older patients as their patients) can further affect how they behave and whether they create additional job resources or demands. For instance, Mazzetti et al. showed that an individual's characteristics (here: positive affectivity such as enthusiasm and negative affectivity such as pessimism) can be an explanation for how physicians perceive their job demands and control [188]. Systematically investigating how HCPs' perceptions of older adults mediate their perceived job demands and whether a positive perception alleviates the perceived difficulty and work burden as described in DP3 would have great potential [145].

In general, there is a considerable gap in researching and evaluating care models or PCC regarding outcomes personally relevant for HCPs, such as work satisfaction, well-being, stress level or attitude change [116]. Consequently, designing ambulatory healthcare for the very old must necessarily include the investigation of HCPs' well-being and attitudes and measures to decrease the burden. Hence, job resources enabling the path of job motivation and buffering demands [129, 130] should also be explored in the context of caring for older adults. In DP3, the most important resources in enabling the provision of good healthcare were found in HCP networks and well-functioning teams [145]. However, a few participants also described reciprocity and valuation from the older patients and participating in their life stories and experiences as resources [145]. Hence, a positive contrast to a negative perception of older people in healthcare could make a job demand a job resource.

8.5 Summary

This chapter discussed the results of the dissertation in the context of further studies and theoretical approaches useful to further understand and apply them to practice. One of the focal points of the results' discussion is that what is considered *good* ambulatory healthcare in old

age equates to PCC drawn from the perspectives of both older people and HCPs. However, while HCPs and existing care models developed by professionals referred to healthcare structures to change and improve healthcare for the very old, the latter themselves especially emphasised the role of building strong, personal care relationships to achieve good healthcare.

Understanding health and well-being and the role of ambulatory healthcare in old age were discussed further. The core motives inductively meta-synthesised from empirical qualitative studies in DP1 showed compelling similarity with Abraham Maslow's theory of human motivation and the SOC proposed by Aaron Antonovsky as a core component of his salutogenic model. It was concluded that older people pursue growth orientation and health orientation in their lives and that the described features of ambulatory healthcare can help them move on a continuum of fulfilling their core motives, while the core motives could also be varyingly important in different phases of, e.g., a persisting health condition. This orientation can also be found in their choice and maintenance of meaningful activities, as is described in the model of selective optimisation and compensation by Baltes and Baltes. The results show that older people wish this to be recognised in healthcare and that healthcare responds to their wish to pursue what they consider meaningful goals. However, it also became apparent that many HCPs hold negative views on caring for older adults and that it is challenging and demanding for them, particularly due to missing system support. Older people internalised ageist stereotypes in healthcare; this was especially striking in their differentiation between themselves and other older people as "bad" healthcare users.

Moreover, older people wish to further discuss existential life issues, also including the end of life, and psychosocial matters. However, this is often avoided in consultations, due to lack of time and lack of communication abilities of both sides and because it is excluded from HCPs' perceived area of expertise. Apart from complexity, these matters make caring for people aged 80 and over particularly challenging for HCPs, posing ongoing job demands as discussed in the context of the JDRM. Job resources in working with the very old should be further explored and developed, particularly regarding perceptions and beliefs of health and life in older age.

The DPs followed an inductive approach in exploring what is relevant in understanding and designing PCC for the very old. The following chapter builds on these considerations and discusses specific implications for research and practice that go further.

9. Implications for research and practice

This chapter presents implications for research and practice regarding patient-centred ambulatory healthcare for the very old. Three areas are discussed: 1) the understanding of ageing and health, 2) the further development of PCC, and 3) the building of a suitable healthcare workforce.

9.1 Debating the understanding of ageing and health

One of the basic implications of the work in hand is that, overall, the meaning of health in older age and the issues being handled in ambulatory healthcare need to be discussed to develop and improve care models. While health sociology has so far mainly focused on subjective theories of health and illness, in light of the demographic change affecting all areas of life, the discussion of health and ageing needs to become part of the analysis of society [189]. Hence, apart from the healthcare sector, society as a whole needs to discuss and define what healthcare should be about, and what is expected from it. Here, sociological and gerontological approaches, particularly life course perspectives, should be considered.

One specific issue is the consideration of old age as diverse, meaningful, forward-looking and as worth living as any other phase of life. While the prevalence of chronic and complex conditions is undoubtedly changing from a population-based view, the very old's health and life situations can be extremely different, and the deficit orientation based on diagnosed conditions in healthcare fails to meet older people's health and life goals. Deficit orientation and reduction of illness deny older people their ongoing potential for growth and well-being. Such views internalised by society agents of the healthcare system result in treating older people inadequately [4]. For example, agreeing that in older age, prevention, social welfare, or having good teeth are *still worth investing in* has the potential to delay and comprise morbidity and ensure ongoing social participation and subjective well-being [4, 34, 190].

Ideally, healthcare systems, or at least the ambulatory healthcare sector as the area closest to people's reality of living, should be designed to ensure that all people unfold their health potential. The core motives and related theories discussed in Chapter 8.2. provide a good basis for that. Promising approaches could be the further investigation of older people's health and well-being from a salutogenic view with a particular emphasis on older people and implementation in ambulatory healthcare. Taking another fundamental perspective of what desirable and achievable goals in healthcare are could also help HCPs feel more confident and well in caring for older adults, resulting in less "failure" regarding the curing of diseases, and the focus on resources and individual patient goals could make growth potentials in older people visible. Moreover, a societal agreement and commitment regarding what healthcare should deliver, also in old age, would entail the structures and means provided for healthcare. Since healthcare will, however, be a field of conflict between a society's limited resources and a

variety of demands, care models should be implemented that are suitable to address the necessary changes with the resources at hand.

9.2 Developing and implementing patient-centred care models

The similarity between the model of desirable ambulatory healthcare resulting from this dissertation and the integrative conceptualisation of PCC [15, 18] demonstrated that patient-centredness seems indeed suitable to address the needs of the very old and ageing population. From the results of this work, PCC for the oldest means a stronger orientation on individual life courses, goals and personal growth in late life, as can be seen in the core motives [137]. Designing patient-centred, health- and growth-oriented healthcare offers the opportunity to encounter demographic challenges and ensure health and well-being until and even at the end of life [4, 142, 184]. This could open untapped potentials in the compression of morbidity, and hence, less burden on the healthcare system and healthcare [190]. Regarding PCC, the conclusions from this work are twofold:

Firstly, PCC as a model of care should be pursued to design ambulatory healthcare for the ageing population. This challenges the conviction that this model would not be preferred by the older generation [112]. In contrast to how care models for older people have up to now mainly been conceptualised, without equal involvement of the target group itself (see Chapter 3), older people should constantly be involved. The results from this dissertation can deliver a blueprint to design PCC for older people. For instance, as the systematic appraisal of confidence in the evidence on this matter in DP1.2 showed, it is also a map to show where further exploration of older people's views is needed [139]. A particular chance for the involvement of older people in the development and implementation of care models is the depletion of ageist stereotypes and deficit-oriented views on older people and their health.

Secondly, PCC as a (theoretical) concept benefits from the inclusion of the perspectives of the very old as provided in this work. People aged 80 and over can be considered a hard-to-reach group [191] and have seldom been adequately depicted in studies on PCC. These usually comprised younger samples of, e.g., patients with chronic conditions [18, 192, 193] and, generally, studies up to now have tended to summarise the very old in the category of aged 60/65 or older [4, 62], despite the fundamental changes in health and living conditions around the age of 80 (see Chapter 2). PCC that meets the needs of the oldest would mean meeting the needs of most of the population as everyone hopes to grow old. Future research and development of PCC should hence comprise a life course perspective.

9.2.1 Further development of patient-centred care: Focusing on relationships

One of the core differences between the existing conceptualisation of PCC and the results of this work, despite the general similarity, is the dominant wish of older people to build deep relationships with their HCPs. As can be seen from the care models in Chapter 3, more effort has been made to improve healthcare structures or single interaction elements in improving

healthcare for older people. This also seems to be true for the understanding of PCC: A systematic review of Langberg et al. [194] investigating how the concept of PCC developed in the past 20 years found that four dimensions were still in line with Mead's and Bower's concept published in 2000 [110]: biopsychosocial perspective, patient-as-person, sharing power and responsibility, and therapeutic alliance. The dimension *doctor-as-person* disappeared, however, while *coordinated care* was added [194]. As the authors discussed, this may reflect the higher complexity of healthcare systems [194]. Aspects of care coordination or healthcare structures may also be easier to operationalise for change. In light of this dissertation's results, this implies the focus on the development and implementation of PCC has not been in the direction of what older people need and wish to be cared for well.

This implies a "back to the basics" if Rogers' model of person-centredness is considered the origin of PCC (see Chapter 4). Rogers also speaks of a growth-promoting climate to support clients, considering their past and future development and emphasises the role of good, trustful working relationships [104]. While in the middle-aged adult population, the focus on patient-centredness due to its fit to the medical and healthcare context as compared to the more therapeutically oriented person-centredness seems to make sense, ageing with its special health challenges and according to developmental tasks could benefit from more person-centredness in patient-centredness. This might even or especially be the case if older people cannot find or formulate appropriate life and health goals for them; therefore, they need more support in this regard. The missing inclusion of older people's perspectives in most care models developed so far could explain why such aspects had been dismissed and hence, why some models could not or not fully prove effectiveness. Consequently, the full potential of care models to help older people follow positive health trajectories as well as they can is not exhausted. To master the challenges of demographic change, reach positive health trajectories and work towards compression of morbidity, this potential should urgently be used [4].

What can also be learned from this work is that implementation of real PCC and investment in personal, and social care interaction is still rare. Similarly, van de Pol et al. concluded from interviews and focus groups with primary HCPs and care home residents on quality care provision that

realising successful care intervention is an undertaking that requires mutual understanding of the expectations and goals of all the parties involved. Recognition of expectations and goal setting is still in its infancy and the main challenge facing caregivers and patients is to create a system that carries out these tasks as standard procedure [103, p. 506].

So, what do these processes of mutual understanding and building care relationships ideally look like? On this matter, Dewar and Nolan proposed a model of compassionate relationship-centred care in older people's care contexts [195]. Firstly, they point to the need for interpersonal competencies rather than technical skills, and to the need of building personal and relational knowledge. This includes knowing about how people (or patients) form their identity and see themselves and knowing about their values, preferences and beliefs [195]. Therefore,

appreciative conversations, i.e., more than conversations focused on the current reason for a healthcare contact, are required. Dewar and Nolan propose four strategies to achieve such conversations: 1) recognising emotions and expressing feelings, 2) asking about current feelings to connect with others, 3) becoming aware of how all involved persons feel about experiences, and 4) supporting people to exchange and react to feedback [195]. The authors summarise which knowledge, skills and values are needed for this:

- willingness to negotiate and compromise;
- willingness to see another perspective;
- promoting and accepting the emotions of others;
- sharing personal information;
- openness to other ideas;
- sharing insights when things are not going so well;
- and recognising what people are good at [195, p. 1256].

The accordance with this dissertation's results on how older people want to be seen holistically and understood as persons and their wish to discuss life goals and existential questions strengthens this concept [137, 139, 142]. In a systematic review on quality in care relationships in long-term care settings, HCPs' encouragement and emotional investment, and trust and social interaction were also identified as relevant determinants [196]. Showing affection and compassion in verbal and nonverbal communication was also an important part of compassionate nursing care identified by Tehranineshat et al. [197]. Hence, while most studies on compassionate relationships with older people are from institutionalised settings, the accordance with the results of this work suggest transferability to community and ambulatory healthcare settings.

From a professional, moral understanding of caring well for patients, some might be convinced this is already part of HCPs' job. However, the frequent complaints of HCPs about the exceeding psychosocial issues of older patients that have no place in the consultation or should be outsourced to other professions [145] show that a gap exists between a professional, moral idea and how the practice of the own job is understood and realised (see Chapter 8.4). Vogt argues that physicians up to now learn communicative strategies especially to ensure patients behave compliantly and thereby lead to the result the physician considers desirable or good care [198]. A study by Neumann et al. discussed empathy, a key element of care quality and patientprovider relationships, as a means to help HCPs to perform necessary medical tasks that need information [199]. While empathy is principally a fundamental component of PCC and offers considerable therapeutic potential [199, 200], this reveals that the uptake of PCC, empathy and SDM in debates around actual practice change may rather be understood as tools to fulfil regular medical tasks than as a true change what HCPs believe is their job. Interestingly, the urge to outsource psychosocial or relationship elements of caring from medical interactions and physicians' struggle to change their professional role towards including such elements were already described by Balint and Balint in their seminars to develop PCC in 1969:

First, it seems as if our doctors felt compelled to identify with two professions when they joined our seminars; the profession of the general practitioner and the profession of the psychiatrist and psycho-analyst. [...] It was important to them to preserve their identity as general practitioners; there were times when they strongly identified with us, but there were times when they did not wish to do so. Secondly, they saw us, on the one hand, as trying to turn them into psycho-analysts, without the time or the opportunity to do so [...]. They wanted to show us how exacting our demands were on them and how frustrating and unrealistic. They thought that when we expected them to do more than they did we did not realize how good they were anyway [108, p. 270].

Hence, what is important to further efforts in developing and implementing PCC effectively for older people is the question of how HCPs understand and realise their role. While this is an important result of the core of this work, it emphasises how such models, frameworks and conceptualisations will fail if they do not simultaneously take up and initiate discussions on the understanding and value of health, age, what is expected from healthcare interactions and professional roles. An important step would be investing in research and promotion of what makes caring for older people and engaging in relationship-building attractive, rewarding, and a resource for HCPs instead of understanding and teaching it as a tool to effectively gain necessary information or reach compliance [201]. This could be the mediator between HCPs' general ideal of PCC and caring well for the oldest, and their actual behaviour, which might be needed to change their roles and practices.

9.2.2 Integration of oral health and healthcare

Another area of action concerns the fact that although comprehensive care overcoming the borders of healthcare sectors and professions and disciplines is warranted, oral health care is rarely incorporated. While in general, the health issues of older people have been recognised and addressed by governments, this is rarely the case regarding oral health and dental care, despite the increasing treatment needs in older age and the considerate impacts on general health, quality of life and well-being [48, 202]. The lack of consideration of oral health in older people in the development of ambulatory healthcare is serious, as can also be seen in the overview of care models (Chapter 3). As Kossioni criticises, in Europe, public funding for oral healthcare rather decreases and oral health is often ignored in concepts to promote health and healthcare comprehensively for older people [48]. Although the oldest are the fastest-growing age group, efforts rather focused on children and few dentists are trained to treat older people [48], another hint at the underlying assumption that in old age, the battle is already lost. In light of the significance of oral health (see Chapter 2), this means withholding ongoing needs and potentials on being painless, able to participate socially and overall well-being in older age. Consequently, PCC needs to ensure the incorporation of all relevant areas, explicitly oral health and healthcare. While studies in oral healthcare settings were also included in the systematic review forming the basis of Scholl et al.'s integrated model of PCC [15], these were outnumbered. Hence, the results of this work should be particularly useful to equally incorporate the area of oral healthcare and as was shown, for example, the aspect of costs was more important compared to GP or specialist healthcare [142]. Ensuring financial structures and support to grant sufficient oral healthcare, raising awareness for oral health among other HCPs and, for instance, including some oral health questions in standard screening procedures of examinations or check-ups at the GP, could already bring great progress [145]. However, this also requires an adequate offer of, e.g., visiting dental care, if needed [145]. Moreover, dental care professionals should be included in the development of care models and treatment concepts. Older people and other healthcare professionals and informal caregivers or relatives need to be made aware of the importance of oral health. Finally, drawing from the insights for general healthcare, building strong care relationships and long-term plans, including long-term prevention measures, check-ups and individual goal setting might be promising approaches to prevent drop-out in older age in oral healthcare.

9.2.3 Why more (reimbursed) consultation time is probably not the solution

An obvious objection to the presented suggestions might be that HCPs would only need more time in their consultations to automatically provide more patient-centred, relationship-oriented healthcare to older people since this is part of their moral and professional understanding. Receiving more reimbursed time for healthcare consultations was also a dominant demand in the survey in DP3 [145] and was identified as a determinant of quality of care relationships [196]. Hence, the implications of consultation length are now briefly discussed.

In a study using videotaped consultations in Norway, Gude et al. showed that consultation time in a GP setting that exceeded 13 minutes (in a scheduled time frame of 15 minutes) significantly correlated with more and especially more psychosocial information exchanged about the patient [203]. In another study investigating the relationship between the depth of the patient-provider relationship and consultation length, having a deep compared to a shallow relationship was associated with a longer consultation, but the difference was only two minutes (overall median consultation length 11.3 minutes and overall median depth of relationship classified as moderate) [204]. In a systematic review, Wilson and Childs found evidence that more consultation time (from the included studies, probably nine versus seven minutes) was associated with less prescription but more advice on how to live healthy and prevention activities, and more personal communication and a holistic patient view [205]. Consequently, more time, or a certain time frame, indeed requires or supports relationship-building and personal communication between patients and providers. However, the necessary additional time is short (about two minutes). Moreover, what counts more for patients might not be the actual consultation length but the perception of being granted enough time. This became apparent from DP2 [142] but was also shown in a British study that found patient satisfaction was not related to the actual consultation length, but to patients' overestimation of length; hence, their perception of having had a positive experience [206]. In a study with people aged 70 and older in eleven European countries, Bastiaens et al. also found that the perception of enough time is related to whether older patients perceive the GP to be interested in them [178].

Consequently, it must be questioned whether (reimbursed) additional time in patient visits automatically results in more SDM, goal setting or discussion of existential questions. For example, a German study on when GPs interrupt their patients at the beginning of a consultation showed that patients were on average interrupted after eleven to 24 seconds (total conversation time six to 11 minutes) [207]. Strikingly, a longer non-interrupted speaking time was *not* associated with an overall longer consultation. Listening well or giving the patient this feeling does not necessarily require more time, but a different mode of communication. This shows how even one of the most frequently demanded aspects might not be the one changing healthcare interactions substantially.

In principle, a small increase in consultation time could be sufficient, but what happens in the interaction and how the older patient feels perceived and valued are more important. However, when examining these studies, it can be also concluded that the "minimum time frame" of planned consultations to enable relationship-building and holistic discussions seems to be between nine and 15 minutes [203, 204]. This is relevant since Germany is among the European countries with the lowest average GP consultation durations (7.6 minutes), compared to the European average of 10.7 minutes and countries such as Belgium or Switzerland at around 15 minutes [208]. Subsequent studies reported approximately nine minutes of average consultation time in Germany [209]. It could be argued that Germany, as a population-rich country with high frequencies of health services use [12, 70], has short consultation lengths because of too few HCPs for too many patients. Indeed, Deveugele et al. found that a higher burden on physicians decreased consultation length [208]. However, the direction of this relationship is unclear; it could also be that due to too short consultation times, patients' needs remain unmet and hence, they need to use health services more frequently. Consequently, being attentive and taking time could be more efficient than rigidness, and increasing time in primary care probably produces more costs initially, but can be offset due to reductions of, e.g., inpatient service use [210, 211]. Since realising a little more time in consultations does not pose a risk to patients or providers, further research on this matter, favourably using study designs allowing for causal conclusions, might significantly improving healthcare.

Moreover, this might decrease HCPs' work burden and increase satisfaction and well-being in their jobs. Physicians in Germany constantly report the perception of needing more time than has been allocated, which poses considerable work pressure [145, 212, 213]. Hence, while more time may not solve all the problems of patient-provider interactions discussed, granting more time through adapted healthcare structures and remuneration could relieve HCPs' work pressure. Less work pressure in turn could offer the needed space to adapt practices and strategies in handling high demands since new or flexible approaches are difficult to adopt during high-demand periods [129, 130].

Overall, the response probably needs to be twofold: Certain minimum time frames are a prerequisite to providing PCC and building relationships, as demanded by HCPs [145].

However, the effect of more time could be overestimated, and a simultaneous change in interaction practices in healthcare consultations and professional roles is needed.

9.3 Building a healthcare workforce for ageing populations

In light of insufficient adaptations of the healthcare system to address the challenges of ageing populations, mastering these is currently up to HCPs and older people themselves. HCPs frequently see themselves confronted with unmanageable demands and mostly wish for more time in healthcare interactions, including the remuneration for that [79, 145]. As has been discussed, the burden is great on HCPs in adapting to the challenges and regarding their workload but also emotionally and regarding conflicts in their professional role.

One proposal is a more general education of physicians compared to specialisation. In Germany, the number of medical specialists is high: specialists are available in inpatient and outpatient settings, which is different to many other European countries [73]. This is questionable since health issues in the ambulatory healthcare sector are often "not severe enough" to justify all those specialists, while many of them, e.g., orthopaedists, actually mostly face conditions such as back pain or arthrosis that could as well be handled by GPs [214]. Consequently, van den Bussche proposes a more general practice focus in medical education [214], and likewise a general focus on the needs of older people is necessary, as can be concluded from this dissertation.

To ensure that HCPs provide the best care for older people and also like their job as a carer for them, how they view and perceive them is crucial, as was explored in DP3 [145]. Studies on nurses and caregivers found that

- relationship-building and trust
- knowledge about ageing and correction of false beliefs about older people
- training and working experiences with older people
- suitable working environments and resources to care for them

are strategies to support positive attitudes and views of older people and their willingness to care for them [26, 215-219]. Aspects that were found to be supportive or valued in older people were their own older age, occupational values, older people's higher appreciation of receiving care and attention, and the emotional intelligence of the care provider [26, 132, 219, 220]. Due to the demographic change, positive views of older people, and the positive effect of working with them are urgently needed to create a suitable healthcare workforce. Direct contact early in the education and training of healthcare professionals could help reduce negative stereotypes, and exploring the value of caring for older people could even be a resource for some. For example, Chênevert et al. found that meaning and recognition from patients as job resources according to the JDRM were negatively associated with depersonalisation, a component of burnout [126].

Overall, while some studies have already investigated students' and nurses' perceptions of older people and their consequences, research and interventions investigating the current practice are lacking, hence, the HCPs currently providing healthcare for older adults. A systematic review by Tullo et al. investigated a range of interventions for undergraduate medical students comprising digital and classroom education, group discussions and clinical simulations regarding older patients [221]. Many interventions targeted the improvement of knowledge, but the effects were often short-term. Regarding attitude change, long-term exposure to geriatric topics was to be preferred over short-term, intense teaching [221]. Interestingly, the authors also concluded that interventions introducing "students to healthy older adults such as senior mentor programmes were more likely to improve student attitude than interventions that exposed students to elderly patients in the clinical environment" [221, p. 1991]. Hence, a geriatrics rotation in a hospital is not sufficient. Similar results were discussed in the systematic review of Samra et al. [222].

What can be concluded from these findings is that

- 1) the need is great for further research on interventions regarding the improvement of attitudes and skills regarding healthcare for older adults targeted at established HCPs;
- 2) research and intervention development should include how HCPs can be relieved and supported in increasing their well-being, job satisfaction and perception of resources in caring for older adults; and
- 3) research and development of healthcare and interventions should focus on how longterm positive perceptions of older people as living meaningful, growth-oriented lives instead of as geriatric patients in great need of help can be implemented.

Most of these conclusions regard necessary overall measures regarding the implementation of PCC as the model that best makes healthcare well-equipped for populations that are on average older and must manage chronic conditions. Policymakers need to address in particular the elements of shared goal setting, personalised care plans and involvement of relatives that are rarely applied yet in primary/ambulatory healthcare innovations, where the main goals are often care coordination and multidisciplinary collaboration [116]. The involvement of all formal and informal stakeholders, including oral HCPs, social services, and community agents, is necessary to build strong networks that facilitate the exchange of the necessary competencies. Among the HCPs surveyed in DP3, building networks was also one of the most important facilitators and according to the JDRM, could be an important resource in enhancing job wellbeing and buffering demands [129, 130, 145]. This is of particular importance since physicians in the ambulatory healthcare sector often work in single-handed practices and hence, may have more autonomy but also a less organisational context that could be supportive [126]. Consequently, no formal structure is ensured for everyone involving professional exchange that is also suitable to serve as a job resource. To build job resources from networks for all HCPs, get all relevant areas involved in such networks and not put an additional burden on HCPs, the development of such network structures needs to be a task of policymakers in healthcare and communities [116].

10. Strengths and limitations

While the possibilities of application of this dissertation's results have been discussed, different strengths and limitations must be considered. As outlined in Chapter 6, the three DPs, building on one another, used different qualitative research methods to explore the perspectives of people aged 80 and over and the physicians and dentists caring for them. The strengths and limitations of the individual studies have already been discussed in the respective articles [137, 139, 142, 145]. However, in using them in this dissertation, this chapter discusses overarching methodological issues.

10.1 Joint conduction of meta-summary and meta-synthesis

The separate and profound conduct of both meta-summary and meta-synthesis for this dissertation is a particular strength in exploring the views of people aged 80 and over. A general advantage of taking together "findings from multiple qualitative studies" is to "provide a range and depth of meanings, experiences, and perspectives of participants across different healthcare contexts" [149, p. 181]. Hence, the meta-summary conducted in DP1.2 was especially useful to explore the range of phenomena and the meta-synthesis (thematic synthesis) conducted in DP1.1 to explore the *depth* of phenomena. Both parts of the DP produced different results and complemented each other in providing a comprehensive understanding of older people's perspectives, although based on the same corpus of qualitative studies. Taken together, the results contribute to the knowledge of the social world and the subjective perspectives of older people. Therefore, their extension of quantitatively-gained knowledge is important [223]. However, the results of DP1 neither replace the single, more in-depth primary studies and their specific aims nor are they suitable to provide "absolute" or "all" knowledge of the phenomenon. In particular, the systematic appraisal of confidence in the evidence provided in DP1.2 should be understood as a map illustrating well and less well-researched features rather than as absolute evidence [139].

10.2 Recruitment and sampling

In DP2 and DP3, empirical studies relying on the sampling and recruiting of participants were conducted. In DP2, a purposive sampling strategy [150, 224] was pursued to enable diversity regarding certain sociodemographics (age, sex, educational status) and health aspects (subjective overall health, subjective oral health) [142]. Since purposive sampling is considered especially suitable to gain appropriate, rich, useful information [224-226], this can be considered a strength of this qualitative study. Moreover, the use of different recruitment strategies, including newspaper advertisements, a financial incentive and no necessity to transport participants for the interview created a good starting position to purposefully select participants [142].

However, the sampling decisions and the final sample do influence the results [226]. Although the concept of bias is harshly discussed regarding whether it is applicable in qualitative research at all [227, 228], and the study did not seek representativeness for all German people aged 80 and over, one issue deserves closer attention. Since DP2 focused on community-dwelling older people, that is, those that are still able to manage their lives mainly on their own, those that did not need to move to an institutional setting, the sample rather comprised the relatively fit "survivors". Therefore, these people might already have an advantage over others regarding their environment, characteristics or behaviours. Indeed, while purposefully recruiting regarding age, sex and educational level worked well, only one-fifth of the sample judged their health status to be rather bad or bad, and the same applied to oral health [142]. This was inherently expected as a considerable research gap related to this target group since prior studies focused more strongly on institutional settings and one research aim was to provide insight into what these people need to age in place as long as possible. Consequently, the results should not be considered biased in the sense that they would be less valid or insightful, but when drawing conclusions from them, these characteristics should be kept in mind. In particular, the possibility that less positively oriented and active people aged 80 and over were ready to participate, despite the widespread visiting approaches of recruitment, needs to be considered.

In DP3, due to the anonymous data collection and no possibility of accessing all eligible persons, for instance, via a register, a convenience sample strategy was pursued. In this strategy, inclusion and exclusion criteria are defined and based on these criteria, recruiting follows "conveniently" the best possible access to participants [145, 229]. To reach participants, recruitment relied on the cooperation of professional networks and organisations to forward information on the study and the survey link [145]. As discussed earlier, qualitative research is not about statistical representativeness; however, who became part of the sample influences the results. As such, especially the role of gatekeepers and participant self-selection should be considered. Overall, 45 organisations representing physicians and dentists were informed about the study and asked for support. This included the four associations of SHI physicians and dentists in this area, and all area- or speciality-related networks of physicians and dentists that could be contacted via e-mail or telephone [145]. A total of 14 organisations ensured their support. These comprised one association of SHI dentists, both regional associations of GPs, and nine area- or speciality-related networks [145]. Among those reached through the organisations, it can be assumed that the actual participants were possibly more open, willing, or interested in the study's topic (self-selection) [224, 225]. This is important for the results since it may be correlated to how the participants perceive older patients, which attitudes they have and how they interact with them, e.g., physicians being interested in older people, and holding positive attitudes, may have been more open and interested in participation. A hint concerning this assumption is the fact that nearly all participants stated they felt well-trained and educated regarding caring for older people, so they may have already chosen certain training opportunities based on their interests.

Overall, this qualitative study did not seek statistical representativeness but broad and deep insights into the participants' perspectives, to understand more about the practice of caring for people aged 80 and over. Although the convenience sampling strategy, and in particular the dependency on gatekeepers, has its difficulties, the chosen design of an anonymous, self-administered, flexible and time-and-date-independent qualitative-only survey can be considered a strength. In particular, the design was more open to a range of participants and their practical realities compared to, e.g., interview studies recruiting participants via teaching practices in a decidedly academic research environment. The potential of the qualitative survey design to reach a broader range of experiences, though, does not seem to be exhausted in light of the smaller range of specialities that are represented in the sample. However, regarding the considerable research gap in insights into physicians' and dentists' views and practical realities in caring for people aged 80 and over, DP3 provided unique and valuable results [225], comprising a larger and more diverse qualitative sample than such studies usually do.

10.3 Qualitative nature of the qualitative survey

In DP3, a qualitative survey in a self-administered online mode was conducted. This study design is still rather uncommon as part of qualitative research [151, 230]. Qualitative surveys have a range of advantages over methods such as interviews, especially when realised online: they involve low costs, provide easy and widespread access, are flexible in time and date and consequently are less burdensome for participants. Hence, qualitative surveys are especially useful in 1) reaching hard-to-reach groups that are, e.g., limited in their time resources, and 2) diversity regarding easy access for a range of groups, who may also be spread geographically [151, 230]. Moreover, due to the anonymity of survey completion, participants might be more open and willing to participate or explain their views, especially when the topic is sensitive or related to strong social or professional norms [151, 230]. These were strong advantages in researching physicians and dentists of different specialities and in the ambulatory healthcare sector in which the target group is widely spread over single practices. Moreover, the method made it easier to gain insight into the breadth of the group instead of only reaching certain official representatives that might be "the usual suspects" [230, p. 19] as might be the case in more burdensome interviews [151, 230].

As examples, mainly in the field of psychology, from Braun et al. [151] and Terry and Braun [230] show, *fully* qualitative surveys that "prioritise qualitative research *values* alongside qualitative techniques" [151, p. 1] offer great potential to explore a range of questions, diversity of experiences and practices, especially in sensitive contexts or hard-to-reach-groups [151, 230]. However, since the research tool is fixed and cannot be flexibly adjusted during data collection, good preparation is needed to ensure that the resulting answers provide enough depth to be useful for qualitative analysis and that participants would complete the survey [151, 230]. Therefore, the qualitative survey in DP3 was extensively pretested and iteratively developed [145]. To ensure transparency and enable further qualitative survey research in the field of

health services research, the full pretest report was provided as an online supplement to DP3 [145], which can moreover be considered a strength of the project.

Another concern regarding qualitative surveys is that the answers might be too short and too uninformative for qualitative analysis [151], particularly in comparison with interviews [151]. However, as Braun et al. [151] explain, the answers might be more dense but still informative and valuable. This was also observed in DP3: in general, the length of the descriptions varied between one line and five lines per question, while the answers were mostly focused accounts rather than full sentences [145]. Hence, although the answers were shorter than in interviews, due to their density, the relatively large sample of 77 included cases, and the final analysis across the whole dataset, DP3 provided diverse insights into physicians' and dentists' perceptions, practices and their meanings, while also allowing for in-depth exploration [151, 230]. Therefore, it can be considered a good example of what qualitative surveys can offer health services research. Although the range of participants and insights was probably more diverse compared to designs such as interviews, as discussed earlier, it still must be noted that DP3 did not unfold the full potential of a qualitative survey in reaching an even broader diversity, as can be seen in the limited number of medical specialties participating.

10.4 Summary

Altogether, this dissertation is based on three sequential projects, each applying different qualitative research methods to gain insight into the perspectives of people aged 80 and over and of physicians and dentists regarding ambulatory healthcare. As such, the methodological approach was patient-oriented, with its results contributing to the development of patient-centred ambulatory healthcare in old age. The combination of methods and perspectives and the sequential project structure supported the development of quite dense results, comprising breadth and depth. In particular, the use of new designs, the transparent reporting and provision of research material whenever possible [225], and particularly the discussion of current methodological critique have the potential to further advance qualitative research in the exploration of stakeholders' perspectives.

The results are not suitable to be generalised in a sense of statistic representation. This is partly because the dissertation aimed to gain subjective insights and therefore used qualitative methods. It is also due to explicitly made decisions in sampling and recruiting that have been disclosed and discussed as transparently as possible. What finally arises from the results of DP1-DP3, taken together, are theoretical insights [231] that can, considering the circumstances of their development, be transferred and used to develop healthcare on the micro level toward PCC. This is particularly valuable in light of prior research gaps regarding ambulatory healthcare in old age, oral healthcare, and explorations of the perspective of healthcare professionals across disciplines.

11. General conclusion

This dissertation aimed to describe and explain what matters in developing patient-centred ambulatory healthcare for people aged 80 and over. In three DPs, the perspectives of community-dwelling people aged 80 and over, physicians and dentists regarding ambulatory healthcare were investigated and discussed to provide an understanding of the necessary elements and developments for age-appropriate healthcare.

It is apparent that community-dwelling older people with a variety of health conditions think and wish their healthcare to be resource-oriented, and that they emphasise which activities are meaningful to them and what they do to maintain them. Considering the goal of achieving the best well-being for all, and in the light of increasingly needed maintenance of autonomy and self-care in older age due to the demographic change and its challenges, this is good news. However, to do so, older people need support and encouragement, especially from ambulatory healthcare services. This can take place through well-established trustful relationships, individualised goal setting, decision-making and treatment. Besides a description of favourable ambulatory healthcare, this dissertation developed three core motives as an explanatory basis for older people's preferences and behaviours: feeling safe, feeling like a meaningful human being, and maintaining control and independence. These core motives reflect older people's general health orientation and growth orientation in healthcare.

By contrast, older people have internalised negative images of older people in the healthcare context and explicitly express how they feel devalued due to their older age. Frequently, they encounter deficit-oriented concepts of age and health in healthcare. It was shown that HCPs often characterise people aged 80 and over as challenging and complex and that caring for them was perceived as burdensome, also due to more psychosocial aspects to be considered. Societal and professional debates about the core of ambulatory healthcare and what should be expected are necessary. Future research should also consider the perceptions of HCPs regarding older patients and the specific job demands and resources in caring for them. Moreover, innovations in care models should include outcomes relevant to them, such as job satisfaction, well-being or attitudes towards their patients.

The results at hand confirm PCC as an appropriate concept to meet the challenges of demographic change. On this matter, this dissertation's results question the assumption that a paternalistic, classical doctor-centred provision of healthcare would be preferred in the older age group. Applying the results to the concept of PCC, it seems that older people more strongly emphasise dimensions of relationship and communication. Since care models developed for the older population have mostly focused on healthcare structures, investing in and researching care relationships could have great potential.

12. References

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Überblick über die Publikationen und Erklärung über die Beiträge

1. **Angélique Herrler**, Helena Kukla, Vera Vennedey, Stephanie Stock. What matters to people aged 80 and over regarding ambulatory care? A systematic review and metasynthesis of qualitative studies. *European Journal of Ageing* 19, 325-339 (2022). https://doi.org/10.1007/s10433-021-00633-7

Impact Factor zum Zeitpunkt der Veröffentlichung: 2.711

Angélique Herrler, Stephanie Stock und Vera Vennedey haben die Studie konzipiert und die Methodik erarbeitet. Angélique Herrler hat das Projekt koordiniert und die Suche nach einzuschließenden Studien durchgeführt. Angélique Herrler und Helena Kukla haben das Screening der einzuschließenden Studien durchgeführt und die eingeschlossenen Studien systematisch bewertet. Angélique Herrler analysierte die eingeschlossenen Studien in Kooperation mit Helena Kukla. Angélique Herrler erstellte den Manuskriptentwurf. Angélique Herrler überarbeitete den Manuskriptentwurf in Zusammenarbeit mit Helena Kukla, Vera Vennedey und Stephanie Stock. Alle Autorinnen haben das Manuskript gelesen, überarbeitet und ihre Zustimmung zur Publikation erklärt.

2. **Angélique Herrler**, Helena Kukla, Vera Vennedey, Stephanie Stock. Which features of ambulatory healthcare are preferred by people aged 80 and over? Findings from a systematic review of qualitative studies and appraisal of confidence using GRADE-CERQual. *BMC Geriatrics* 22, 428 (2022). https://doi.org/10.1186/s12877-022-03006-6

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Angélique Herrler, Stephanie Stock und Vera Vennedey haben die Studie konzipiert und die Methodik erarbeitet. Angélique Herrler hat das Projekt koordiniert und die Suche nach einzuschließenden Studien durchgeführt. Angélique Herrler und Helena Kukla haben das Screening der einzuschließenden Studien durchgeführt und die eingeschlossenen Studien systematisch bewertet. Angélique Herrler analysierte die eingeschlossenen Studien in Kooperation mit Helena Kukla. Angélique Herrler erstellte den Manuskriptentwurf. Angélique Herrler überarbeitete den Manuskriptentwurf in Zusammenarbeit mit Helena Kukla, Vera Vennedey und Stephanie Stock. Alle Autorinnen haben das Manuskript gelesen, überarbeitet und ihre Zustimmung zur Publikation erklärt.

3. **Angélique Herrler**, Helena Kukla, Anna Greta Barbe, Vera Vennedey, Stephanie Stock. Characteristics of desirable ambulatory health and oral healthcare from the perspective of community-dwelling people aged 80 and over – A qualitative examination. *Age and Ageing* 51(11): afac258 (2022). https://doi.org/10.1093/ageing/afac258

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4. **Angélique Herrler**, Lisa Valerius, Anna Greta Barbe, Vera Vennedey, Stephanie Stock. Providing ambulatory healthcare for people aged 80 and over: Views and perspectives of physicians and dentists from a qualitative survey. *PLoS ONE* 17(8): e0272866 (2022). https://doi.org/10.1371/journal.pone.0272866

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Angélique Herrler, Stephanie Stock und Vera Vennedey haben die Studie konzipiert und in Kooperation mit Anna Greta Barbe die Methodik erarbeitet. Angélique Herrler hat das Projekt koordiniert und die Datenerhebung durchgeführt. Angélique Herrler hat die Daten in Kooperation mit Lisa Valerius analysiert. Angélique Herrler erstellte den Manuskriptentwurf. Angélique Herrler überarbeitete den Manuskriptentwurf in Zusammenarbeit mit Lisa Valerius, Vera Vennedey, Anna Greta Barbe und Stephanie Stock. Alle Autorinnen haben das Manuskript gelesen, überarbeitet und ihre Zustimmung zur Publikation erklärt.

Appendix: Publication 1

Publication 1

What matters to people aged 80 and over regarding ambulatory care? A systematic review and meta-synthesis of qualitative studies

Angélique Herrler, Helena Kukla, Vera Vennedey, Stephanie Stock

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REVIEW



What matters to people aged 80 and over regarding ambulatory care? A systematic review and meta-synthesis of qualitative studies

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Abstract

The growing percentage of the population aged 80 and over is challenging for healthcare systems, as frailty and other complex health issues are common in this age group. In order to provide patient-centered ambulatory healthcare, their preferences and expectations need to be explored. Therefore, the aim of this study was to systematically search for and synthesize qualitative evidence on how people aged 80 and over believe ambulatory healthcare (medical and nursing care) should be delivered to them. Medline, PsycINFO, CINAHL, Web of Science Core Collection and Google Scholar were searched for full research reports of qualitative studies focusing on the preferences, wishes, needs, expectations and experiences of people aged 80 and over regarding ambulatory medical and nursing care. The results were screened by two independent reviewers using a two-step approach. The included studies were meta-synthesized using Thomas and Harden's 'thematic synthesis' approach in order to gain a new, second-order interpretation of the findings of the primary studies. In the intermediate synthesis step, 14 aspects of healthcare structures and care relationships were identified as relevant. Based on these, three underlying wishes were found: feeling safe, feeling like a meaningful human being, and maintaining control and independence. The results of this review are in line with other research, such as reviews focusing on the preferences of the younger age group (65–80). However, the importance of aspects of care relationships as an integral part of favorable ambulatory healthcare and the wish to be strengthened as a meaningful human being are emphasized more strongly.

 $\textbf{Keywords} \ \ Aged \cdot 80 \ and \ over \cdot Patient-centered \ care \cdot Ambulatory \ care \cdot Qualitative \ research \cdot Patient \ preferences \cdot Systematic \ review$

Introduction

The United Nations (2019) estimate that by 2050, the number of people aged 80 and over will triple to 143 million globally. For these people, the "oldest old," an important aspiration is ageing in place. This means to enable older people to continue living in their home and known environment with as low dependency levels as possible and therefore,

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avoid institutionalization and transition to a nursing home (Houben 2001). Older people show a preference for ageing in place to maintain their relationships and autonomy (Costa-Font et al. 2009; WHO 2015b; Wiles et al. 2012).

However, this is particularly challenging due to health-related impairments (Betini et al. 2017; Hajek et al. 2015). Although the effects of ageing vary between individuals, research conducted in recent years indicates a considerable deterioration in physical health status among very old people. In addition to higher multimorbidity among this age group, frailty becomes increasingly common (Collard et al. 2012; Marengoni et al. 2011; Rockwood et al. 2011; Rosero-Bixby and Dow 2009). Frailty, a state of general vulnerability, is the result of decreased capacities in different body systems interacting (Fried et al. 2004; WHO 2015b). It increases the risk of further geriatric syndromes that are highly prevalent from the age of 80, such as falls and urinary incontinence (Inouye et al. 2007; WHO 2015b). Subsequently, these older people need help with one or more



aspects of daily life, and are frequent users of the healthcare system (Marengoni et al. 2011; van den Bussche et al. 2011; WHO 2015b).

Since a considerable proportion of the ageing population's health issues are complex and chronic in nature, the purpose of healthcare services is expected to shift from acute care and curing toward (1) chronic care and (2) individualized goals and encouraging active involvement of patients. There are two major propositions for reorienting healthcare to address this shift. The first proposition is a stronger focus on ambulatory care, i.e., the provision of a broad range of healthcare services including prevention, curation and rehabilitation on an outpatient basis (Berman 2000). Ambulatory care is of particular importance for ageing in place and considered to best manage the requirements of complex and chronic care, especially regarding timely access, care coordination and cost-efficiency (WHO 2015a). Secondly, models of patient-centered care (PCC) are frequently proposed to encourage individualized care, and are now being called for by important international organizations such as the World Health Organization (2015b). In contrast to episode-based clinical care, where patients are rather passive, the core of these models is to actively involve patients and incorporate their individual values, needs and preferences (Lusk and Fater 2013; Scholl et al. 2014). As such, in order to bring healthcare systems in line with the demographic shift, older people's subjective needs and preferences, especially regarding ambulatory care, should be explored and used as the basis for adaptations.

Previous approaches to examining older people's healthcare needs and preferences have focused mainly on the 60 and over age group. Although people aged 80 and over were not excluded in these reviews, most participants were below 80 years of age (Gonzalez et al. 2019; Gregory et al. 2017; Holm et al. 2013; McGilton et al. 2018). Therefore, the results may not be representative for the oldest-old, especially regarding their special health issues as mentioned above. Furthermore, previous studies have focused on institutional settings such as hospitals and nursing homes (Bridges et al. 2010; Maurer et al. 2019). This issue was addressed by a recent scoping review that focused on home environments, but only included studies on home healthcare recipients (Dostálová et al. 2020). As such, the variety of healthcare needs and preferences, including those for older people who are in good enough health to manage on their own or with help of relatives in the ambulatory setting, remains unclear. To fill this research gap, a broader systematic review covering the subjective perspective of people aged 80 and over regarding ambulatory care is needed. Thus, the aim of this study was to synthesize qualitative evidence on the design of ambulatory care as desired by people aged 80 and over. The overall research question was: What matters to people aged 80 and over regarding ambulatory care?



A systematic literature search and a thematic synthesis of the findings were conducted in order to provide a metasynthesis. Qualitative meta-synthesis aims to transform the findings into integrated descriptions and explanations of the qualitative research phenomenon (Sandelowski and Barroso 2007). For this review, Thomas and Harden's (2008) inductive "thematic synthesis" approach that focuses on the integration of individual experiences and perspectives was applied.

The review was prospectively registered at PROSPERO (record number: CRD42020158107). Reporting is based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, Moher et al. 2009) and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement (ENTREQ, Tong et al. 2012).

Search strategy

In order to develop the search strategy, the following review question was formulated based on the overall research question: What are the preferences, needs and expectations of the oldest-old regarding ambulatory care, from their perspective? Since these terms are often used inconsistently or interchangeably in qualitative studies on healthcare structures, they were found to be appropriate to represent "what patients want from their healthcare" following Street et al. (2012, p. 168). Combined search terms and controlled vocabulary relating to people aged 80 and over, preferences and ambulatory medical and nursing care were used. The search was limited to qualitative studies because the area of interest was the subjective perspective of the older persons. The search strategy was piloted in PubMed, together with the inclusion criteria. The final strategy (Online Resource 1) was adapted to the other databases.

The first author searched electronic bibliographic databases related to medicine and health sciences (Medline via PubMed, PsycINFO, CINAHL, Web of Science Core Collection) for full primary research reports from inception to October 2019. A search in Google Scholar and a forward and backward citation search of included studies were also conducted. Research reported in English, German and Dutch was included. A search update was carried out in September 2020, but no recent studies were eligible for inclusion. The retrieved results were merged into the citation management software EndNote X9 (Clarivate Analytics, Boston).



Selection of studies

Studies were screened using a two-step approach: firstly, two authors (AH, HK) independently screened all the abstracts for eligibility. Unclear cases were discussed until consensus was reached. Secondly, the full texts of the included abstracts were assessed for inclusion. In case of disagreement, a third reviewer (VV) was consulted in order to reach consensus. The authors of studies with missing information (e.g., regarding the sample's age structure) were contacted.

Qualitative studies in which people aged 80 and over (median or average age of study population: at least 80 years) who live at home expressed their views were eligible for inclusion. In addition to studies reporting directly on care preferences, needs and expectations, studies on participants' positive and negative care experiences were also included, because it was expected that preferences would be derived from these descriptions. Studies on end-of-life care were excluded, since the goals of this can differ strongly from other areas of (geriatric) care. The search and selection criteria are summarized in Table 1.

Quality appraisal

Two authors (AH, HK) independently evaluated the quality of each included study. Since our aim was to synthesize the qualitative studies' findings and provide a second-order

interpretation, we were especially reliant on their validity, meaning that the findings are reasonable representations of the original data and their contexts, and are convincing and coherent (Leung 2015; Whittemore et al. 2001). This means that data, data collection and analysis had to be appropriate to the respective qualitative research aim (Leung 2015). Therefore, we used the Quality Appraisal Checklist for Qualitative Studies of the National Institute for Health and Care Excellence that examines the appropriateness and coherence of the study instead of item reporting (NICE 2012). Unclear cases were discussed with a third reviewer (VV) where necessary. Quality appraisal was used not to weight individual study contributions, but to evaluate the robustness of the synthesized findings.

Analysis and synthesis

The results of the included studies formed the basis for the synthesis. In studies reporting on different participant groups, only those parts explicitly referring to the perspective of people aged 80 and over were used. The analysis was conducted using MAXQDA Analytics Pro 2020 (VERBI software, Berlin). In accordance with Thomas and Harden (2008), the analysis consisted of three steps: inductive line-by-line-coding, development of descriptive themes, and development of analytical themes (integration and explanation of the findings).

Table 1 Search and selection criteria

	Inclusion	Exclusion
Population	 Participants aged 80 or older Mean age or median age of study population is 80 or older Mixed participant groups: inclusion, if results for people aged 80 or older can be separated 	 Mean age or median age is under 80 years Mixed participant groups: exclusion, if results are mixed and cannot be separated for people aged 80 and older
Phenomenon of interest	Studies on preferences, wishes and needs of older people regarding formal/professional medical or nursing care Studies on care experiences, problems, determinants and factors of care regarding formal/professional healthcare	 Studies on end of life care, particular therapies Studies on technical devices and applications Studies not focusing on healthcare Studies on informal/unprofessional care or volunteer work
Context/Setting	 Ambulatory/outpatient healthcare (medical and nursing care) Primary healthcare, general practice Home healthcare Participants living at home 	 Participants living in an institutional care setting Hospital care
Study design	Qualitative studies focusing on the perspective and descriptions of older people (interviews, focus groups, group interviews with semi-structured interview guides or open-ended questions)	 Non-qualitative study designs Studies not focusing on the own perspective and descriptions of older people, e.g., surveys, observations Mixed-methods designs in which qualitative findings of older people's perspectives cannot be separated
Language	English, German, Dutch	Other languages
Type of research report	Full research reports	Poster abstracts, editorials, comments, book chapters, study protocols



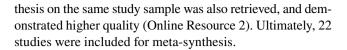
Firstly, the findings of the primary studies were inductively coded *line-by-line* with regard to their content and meaning. Two authors (AH, HK) independently coded a random sample of four studies. Secondly, both authors categorized them toward an initial set of *descriptive themes* and discussed their results for consensus. Subsequently, the independently examined eight and nine descriptive themes were refined to a set of ten that described relevant aspects of two dimensions: healthcare structures and care relationships. The remaining studies were coded with these themes and in the final consultation, the set was refined to fourteen descriptive themes (Table 2). Moreover, first ideas to explain the themes were collected during this process.

Thirdly, the similarities and differences in the descriptions of all the aspects were compared theme-by-theme in order to gain an understanding of why they matter to older people and develop saturated analytical themes. Since we were not working with primary data and therefore, could not rely on a concept of saturation based on the emergence of new codes and potentially conducting more interviews, we built on a concept of meaning saturation and the explanatory power of the analytical themes (Hennink et al. 2017; Saunders et al. 2018). This meant that we did not stop analysis at the point of information redundancy but at the point of the best fit between our primary studies' findings and the analytical themes. Therefore, one author (AH) compared the themes and suggested a set of analytical themes that best integrated and explained them based on the earlier collection of ideas. In the next step, this was discussed in the research team and the analytical themes were refined. The two steps were repeated and after the next revision, the second author checked the results regarding the analytical themes to validate them. After this step, minor revisions regarding the analytical themes' wording were conducted and a final discussion with the research team took place that confirmed the analytical themes. While the descriptive themes describe general relevant care aspects, the analytical themes were ultimately understood as the underlying wishes of older people that explained why these aspects are relevant, and what matters to them fundamentally regarding ambulatory care.

Results

Systematic review and quality appraisal

In total, 5576 research reports were identified during the search process. A flowchart for the search and selection process is provided in Fig. 1. Following screening for eligibility, 23 full texts were included for quality appraisal (22 peerreviewed articles, 1 doctoral thesis). During this step, the article by Krothe (1997) was excluded because her doctoral



Characteristics of included studies

Most of the included studies were conducted in Northern and Western Europe (n = 15), and used interviews for data collection (n = 19). The studies comprised 330 eligible older participants in total, approximately two thirds of whom were female. Eight studies assessed the participants' views regarding home care and community-based long-term care, six studies dealt with ambulatory general practice or specialist care. Moreover, three studies examined (preventive) home visits and case management, respectively. While two studies reported that most of their participants perceived their health status to be reasonable to excellent and another two studies focused on dementia patients, the rest of the included studies reported on older people with several varying chronic conditions, multimorbidity, frailty or at risk for functional decline and institutionalization. Therefore, most of the studies did not examine a specific or acute occasion for seeking care, but the older people's general experiences with care they received for long-term conditions and related impairments. An overview of the studies' characteristics is provided in Table 3.

Results of meta-synthesis

We identified three analytical themes as the underlying wishes of older people: (1) feeling safe, (2) feeling like a meaningful human being and (3) maintaining control and independence (Fig. 2). These appear to be of equal importance and do not follow a hierarchy; instead, they rather interact with and complement each other. Despite the second theme that was not present in the studies on case management, the analytical themes represent the diverse range of ambulatory care settings and health conditions of older people as described above. Therefore, the three themes should be understood as set of general underlying wishes of older people regarding ambulatory healthcare structures and care relationships rather than regarding specific treatments or care settings. As the core of the meta-synthesis, the three analytical themes/wishes are described in detail in the following section and complemented by their most significant relations to single care aspects as found in this review.

Feeling safe

The first fundamental wish was "feeling safe." Older people had several fears related to their age (e.g., medical emergencies, consequences of polypharmacy, further physical or mental deterioration) that evoked a strong



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Author(s), Year	Title	Country	Data collection and analysis	Sample	Care setting	Care-related background of the older people
Behm et al. (2013)	Preventive home visits and health—experiences among very old people	Sweden	Semi-structured interviews and phenomenographic method	17 participants (80–92 years, 12 female, 7 male) that were considered to be pre-frail and lived at home	Preventive home visit	Pre-frail patients; perceived health was reasonable to excellent, participants were independent from help
Berkelmans et al. (2010)	Characteristics of general practice care: what do senior citizens value? A qualitative study	Netherlands	Semi-structured interviews and framework method	13 patients (65–91 years, mean age 81.2, 7 female, 6 male) from four GP practices;	General practice care	Four patients with rather bad or moderate perceived health, nine patients with reasonable to excellent perceived health
Bjornsdottir (2018)	'Holding on to life': an ethnographic study of living well at home in old age	Iceland	Interviews and thematic analysis	15 home care nursing clients (82–99 years, 9 female, 6 male) that were considered to be frail	Nursing home care	Patients that were considered to be frail; participants had several different chronic conditions, health status was rather poor
Faeo et al. (2020)	Home-dwelling persons with dementia's percep- tion on care support: qualitative study	Norway	Interviews and hermeneutic approach	12 day care center attendants (69–89 years, mean age 82, 6 female, 6 male) diagnosed with dementia and living at home	Care settings with relevance to dementia patients; focus on day care centers	Patients with diagnosis of dementia recruited in day care centers
Gowing et al. (2016)	Patients' experiences of a multidisciplinary team-led community case management program: a qualitative study	UK	Semi-structured interviews and thematic analysis	16 frail patients (48–90 years, median age 82.5, 11 female, 5 male) and 7 family members	Case management	Frail patients recruited from the Northumberland High Risk Patient Program
Jarling et al. (2018)	Becoming a guest in your own home: home care in Sweden from the perspective of older people with multimorbidity	Sweden	Interviews and content analysis	12 home care clients with multimorbidity (77–90 years, 8 female, 4 male)	Home care	Patients with multimorbidity and several different medical problems; patients received home care and lived alone
King et al. (2018)	Implementation of a gerontology nurse specialist role in primary health care: health professional and older adult perspectives	New Zealand	Semi-structured interviews and content analysis	5 participants who received the intervention (3 female, 2 male (mean age > 80) and 6 healthcare professionals	Case management	Patients at high risk of health and functional decline who received the intervention "primary healthcare gerontology nurse specialist"
Krothe (1992)	Constructions of elderly people's perceived needs for community-based long-term care	USA	Interviews and content analysis	9 clients (65–93 years, mean age 81.4, 7 female, 2 male)	Community-based long- term care	Clients of an Area Agency on Ageing with different conditions and at risk for institutionalization, which needed help with daily activities



Table 2 (continued)						
Author(s), Year	Title	Country	Data collection and analysis	Sample	Care setting	Care-related background of the older people
Martin-Matthews and Sims-Gould (2008)	Employers, home support workers and elderly clients: identifying key issues in delivery and receipt of home support	Canada	Semi-structured interviews and constant comparative method	age 83, 10 female, 4 male) and 11 home care employers and 32 home support workers	Home care	Clients of home support agencies with different durations of home support (2–250 weeks)
Michel et al. (2015)	From real to ideal—the health (un)care of long- lived elders	Brazil	Interviews and thematic analysis	10 basic health unit users (aged 80 or older, 5 female, 5 male) and 10 nursing professionals	Basic health unit	Older people that were assigned to the basic health unit for at least six months, no further description of health background
Modig et al. (2012)	Frail elderly patients' experiences of information on medication. A qualitative study	Sweden	Semi-structured interviews and content analysis	12 frail patients (65–88, median age 80.5, 7 female, 5 male)	General, focus on information on medication	Recruitment from a study that evaluated a case manager model; patients taking cardiovascular medications, had been admitted to hospital twice or more and had four or more outpatient care contacts, needed help with at least two activities of daily living
Moe et al. (2013)	The meaning of receiving help from home nursing care	Norway	Narrative interviews and hermeneutic approach	11 home nursing care clients (80–92 years, mean age 88, 6 female, 5 male)	Home care nursing	recruited through a former study on older people; with chronic diseases (e.g., heart disease, diabetes, visual and hearing impairments)
Sandberg et al. (2014)	Case management for frail older people—a qualitative study of receivers' and providers' experiences of a complex intervention	Sweden	Open-ended interviews and content analysis	14 older people living at home (75–95 years, mean age 83, 10 female, 4 male) and 6 case managers	Case management in outpatient setting (intervention);	recruited during intervention; participants that needed help with at least two activities of daily living, in the past twelve months two or more admissions to hospital or four contacts to outpatient care
Schulman-Green et al. (2006)	Goal setting as a shared decision-making strategy among clinicians and their older patients	USA	Focus groups and content analysis	42 participants in four focus groups (mean age 81, 25 female, 15 male) and 11 clinicians in two focus groups	General, focus on goal setting in clinical encounter	Participants with at average two chronic conditions and mild to moderate functional impairments, assisted/independent living,
Soodeen et al. (2007)	Home care for older couples: "It feels like a security blanket"	Canada	Interviews and thematic content analysis	9 home care clients (70–94 years, mean age 80, 6 female, 3 male) and 9 spouses	Home care	Participants with at least one chronic condition



Table 2 (continued)

Author(s), Year	Title	Country	Data collection and analysis	Sample	Care setting	Care-related background of the older people
Spoorenberg et al. (2015)	Experiences of community-living older adults receiving integrated care based on the chronic care model: a qualitative study	Netherlands	Semi-structured interviews and grounded theory	23 community-dwelling older people (75–89 years, mean age 82, 13 female, 11 male)	Population-based integrated care model (Embrace)	Care receivers of different health profiles and classi- fies as either robust, frail or having complex care needs
Tiilikainen et al. (2019)	"They're always in a hurry"—older people's perceptions of access and recognition in health and social care services	Finland	Focus groups and thematic analysis	19 participants in four focus groups (mean age 80, 15 female, 4 male)	General, focus on health and social care services	Older people living alone who used health and social care services in the past six months; no further description of health background
Toien et al. (2015)	Older users' perspectives on the benefits of preven- tive home visits	Norway	Interviews and hermeneutic 10 users of preventive approach home visits (81–91 y mean age 85.5, 6 fen 4 male)	10 users of preventive home visits (81–91 years, mean age 85.5, 6 female, 4 male)	Preventive home visits	Two patients had only minor health concerns, the others were physically restricted in varying degrees (mainly neurological and musculoskeletal problems); three were considered to be frail
Turjamaa et al. (2014)	Living longer at home: a qualitative study of older clients' and practical nurses' perceptions of home care	Finland	Interviews and content analysis	23 home care clients (mean age 84), and 14 practical nurses	Home care	Clients who received one or two home visits a day
van Blijswijk et al. (2018)	Wishes and needs of community-dwelling older persons concerning general practice: a qualitative study	Netherlands	Group interviews and framework method	24 participants (median age Integrated care trial 85.7, 18 female, 6 male)	Integrated care trial	19 participants with multimorbidity and 17 with polypharmacy, several health complaints and physical impairments
van Kempen et al. (2012)	Home visits for frail older people: a qualitative study on the needs and preferences of frail older people and their informal caregivers	Netherlands	Interviews and grounded theory	11 community-dwelling frail participants (65–90, median age 80, 9 female, 2 male), and 11 informal caregivers	Home visits	Most participants with polypharmacy and varying other conditions such as multimorbidity or cognitive/physical impairments,
Walker et al. (2018)	Dementia assessment services: what are the per- ceptions of older people?	Australia	Semi-structured interviews and content analysis	9 dementia patients (66–90 years, mean age 80, 4 female, 5 male)	dementia assessment services, mainly outpatient specialist services	Patients with a diagnosis of mild dementia



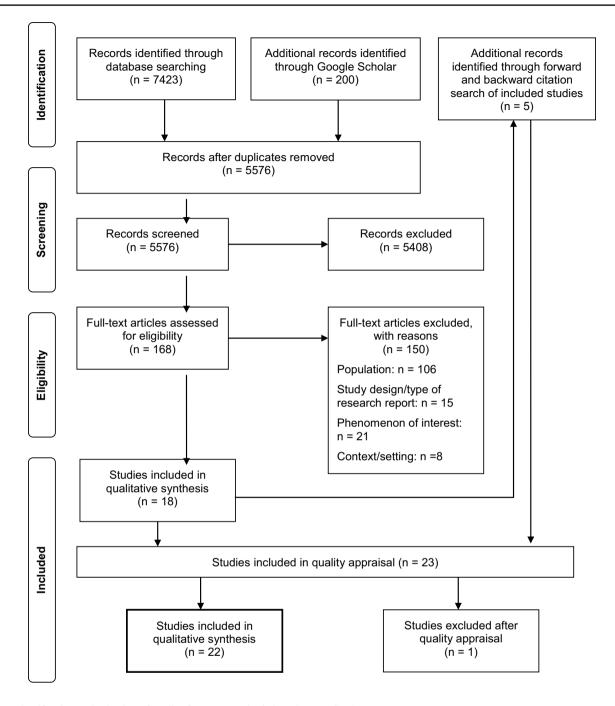


Fig. 1 Identification and selection of studies for meta-synthesis based on PRISMA statement

desire for a "safety net" regarding their healthcare and daily life (Behm et al. 2013; Berkelmans et al. 2010; Faeo et al. 2020; Gowing et al. 2016; Jarling et al. 2018; Modig et al. 2012; Moe et al. 2013; Sandberg et al. 2014; Soodeen et al. 2007; Spoorenberg et al. 2015; Toien et al. 2015; Turjamaa et al. 2014; Walker et al. 2018). An 82-year-old male participant in Toien et al. (2015) said:

The most important is the safety—you know, that someone cares and looks after you and checks that the head is still functioning; that is very reassuring. And knowing you are within the municipality's system (p. 704, preventive home visits).



Table 3 Explanation of descriptive themes

Descriptive theme	Meaning
Healthcare structures	
Time for care	Time that is available for appointments, interactions and care in general
Skills of professionals	Knowledge, technical and communication competencies of healthcare professionals
Sufficient support	Care that is suitable to support the older person with its individual needs
Care coordination	Care that is organized and supervised by a healthcare professional
Access to care	Fast and easy availability of different care services, e.g., specialist care
Continuity and reliability of care	Care that is predictable and provided by familiar persons
Information	Extent, content and manner of information transfer between older person and healthcare professional
Place of care	Regular setting in which care is provided (home/ambulatory versus institutional care)
Care relationships	
Involvement in decisions and care	Role and inclusion of the older person in decision processes and care situations
Care contact as social contact	Interactions with care professionals as meaningful social interactions beyond the main reason for care
Friendliness	Attitude and handling of healthcare professionals toward older people
Personal care relationships	Close and trustful relationships between the older person and healthcare professionals
Activation	Motivation and support for the older person to participate in activities
Open and confidential communication	Atmosphere that allows older people to speak uninhibitedly and bring up their problems

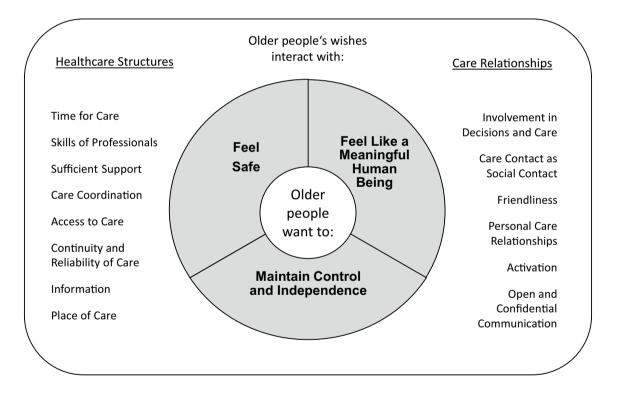


Fig. 2 Results of the meta-synthesis. Analytical themes represent underlying wishes (center), descriptive themes represent relevant aspects of healthcare structures (left) and care relationships (right)

The strongest contributions to a sense of security among older people were found in aspects of the healthcare structures. Older people felt safe when they received the support they considered necessary, i.e., sufficient, attentive care that met their needs and included individual adjustments (Bjornsdottir 2018; Modig et al. 2012; Soodeen

et al. 2007; Toien et al. 2015). The feeling of safety was particularly pronounced when a healthcare professional or case manager monitored their health status and stayed in touch with them (Bjornsdottir 2018; Faeo et al. 2020; Gowing et al. 2016; King et al. 2018; Sandberg et al. 2014; Spoorenberg et al. 2015; Toien et al. 2015; van Blijswijk



et al. 2018). Conversely, participants felt insecure when they did not receive the support they needed (Gowing et al. 2016; Modig et al. 2012). In addition to this, continuous, reliable and predictable care was important to the feeling of safety, while participants feared a high turnover of healthcare professionals (Berkelmans et al. 2010; Bjornsdottir 2018; Jarling et al. 2018; Martin-Matthews and Sims-Gould 2008; Modig et al. 2012; Moe et al. 2013; Spoorenberg et al. 2015).

Another important factor for safety was care coordination. Older people felt relieved and safe when their care was coordinated by a healthcare professional or case manager, i.e., when someone organized their care and ensured collaboration between different healthcare providers (Gowing et al. 2016; King et al. 2018; Sandberg et al. 2014; Spoorenberg et al. 2015; Walker et al. 2018). Sandberg et al. (2014) stated:

[...] case management was experienced as something beneficial and something that could contribute to a sense of security (p. 9, case management).

Moreover, being able to access healthcare (e.g., general practice, specialists) and a familiar contact person quickly and easily when necessary was perceived as essential (Behm et al. 2013; Berkelmans et al. 2010; Moe et al. 2013; Spoorenberg et al. 2015; Toien et al. 2015). Likewise, waiting times and not receiving direct access evoked feelings of insecurity (Berkelmans et al. 2010; Modig et al. 2012). The same applied to information, as shown by a statement in Modig et al. (2012):

If the information was limited and there was no one available to answer questions, there were soon feelings of insecurity (p. 6, information on medication).

Receiving sufficient information regarding their care, such as information on medication, was crucial to helping older people feel safe (Modig et al. 2012; Moe et al. 2013). Information on additional services and care options improved the sense of safety (Behm et al. 2013; Turjamaa et al. 2014), as did experience, knowledge and communication skills on the part of healthcare professionals (Berkelmans et al. 2010; Spoorenberg et al. 2015; Walker et al. 2018).

Other factors important to a sense of safety for older people were found in their care relationships. Close and long-term relationships promoted trust and feelings of safety (King et al. 2018; Sandberg et al. 2014; Soodeen et al. 2007). This was closely linked to open communication; if the communication style between the older persons and their professional caregivers was not confidential and trustful, insecurity and distrust increased (Jarling et al. 2018; Modig et al. 2012).



Feeling like a meaningful human being

This theme represents the external perception and selfperception of aged persons within care relationships. While most of these people had to deal with physical and mental deteriorations such as diminished vision and, consequently, restrictions such as loss of mobility, they focused on the remaining options available to them—they wanted to enjoy their lives despite their old age (Behm et al. 2013; Bjornsdottir 2018; Faeo et al. 2020; Moe et al. 2013; Spoorenberg et al. 2015). The primary studies showed that older people wanted to be seen and accepted as valuable individuals who still act on their own, take pleasure in daily activities and contribute something to society (Behm et al. 2013; Krothe 1992; Martin-Matthews and Sims-Gould 2008; Moe et al. 2013; Tiilikainen et al. 2019; Toien et al. 2015). This was described as being "confirmed [...] as a human being" (Moe et al. 2013, p. 744) and "a wish for dignity, value, and selfesteem" (Toien et al. 2015), p. 706). As one 82-year-old woman in the interviews in Toien et al. (2015) put it:

That I am not just sitting here and am forgotten, but that someone makes me feel that I still have something to contribute. That I'm not just a weak human being who sits here, but I still mean something (p. 707, preventive home visits).

However, the studies revealed that older people endured a variety of negative care experiences. Depending on their interaction with their caregivers, they described feeling unimportant, worthless, vulnerable, helpless, overlooked or inferior, and said they were afforded lower priority and interest because of their age (Behm et al. 2013; Bjornsdottir 2018; Jarling et al. 2018; Modig et al. 2012; Moe et al. 2013; Tiilikainen et al. 2019). This was connected to a loss of privacy (in home care) and feeling like a burden to others (Jarling et al. 2018; Moe et al. 2013; Tiilikainen et al. 2019).

In view of this, it was not surprising that whether an older person felt like a meaningful human being was strongly connected to their care relationships. The most important aspect of this was social contact itself, i.e., conversations and interest toward the older people (Behm et al. 2013; Jarling et al. 2018; Krothe 1992; Moe et al. 2013; Soodeen et al. 2007; Tiilikainen et al. 2019). Soodeen et al. (2007) summarized:

[...] becoming acquainted with their [healthcare worker] beyond interacting about the tasks at hand and enjoying a little casual conversation help[ed] put the [care receivers] at ease (p. 1249, home care).

More explicitly, experiencing friendliness and respect made older people feel valuable, while experiencing rudeness and disrespect made them feel burdensome and unimportant (Bjornsdottir 2018; Jarling et al. 2018; Moe et al. 2013; Soodeen et al. 2007; Toien et al. 2015). Such negative care

relationship experiences inhibited open communication between the older persons and their healthcare providers (Jarling et al. 2018; Moe et al. 2013). Furthermore, receiving the support they needed promoted a sense of meaningfulness among older people. Individual help enabled them to continue doing things they considered important, and therefore improved their well-being (Moe et al. 2013; Tiilikainen et al. 2019; Toien et al. 2015).

Maintaining control and independence

The third fundamental wish identified by the older people was to maintain their control and independence. This related to several aspects of their healthcare structures and care relationships. It became apparent that participants adapted to age-related changes on their own, for instance by giving up certain activities, and that they tried to manage as many things as they could on their own (Behm et al. 2013; Bjornsdottir 2018; Krothe 1992; Michel et al. 2015; Modig et al. 2012; Sandberg et al. 2014; Soodeen et al. 2007). A participant in Soodeen et al. (2007) explained:

You've got more self-worth, you know, thinking, 'well, I can do it for myself yet' (p. 1247, home care).

This illustrates the wish to be independent, and that older people wanted to avoid receiving care and support for as long as possible, because they feared losing control (Behm et al. 2013; Berkelmans et al. 2010; Bjornsdottir 2018; Faeo et al. 2020; Krothe 1992; Sandberg et al. 2014; Spoorenberg et al. 2015; Tiilikainen et al. 2019; van Kempen et al. 2012). Being independent was important to their sense of control and their self-esteem—but they also acknowledged that they needed help to maintain their independence (Behm et al. 2013; Bjornsdottir 2018; Faeo et al. 2020; Gowing et al. 2016; Krothe 1992; Soodeen et al. 2007; Toien et al. 2015).

On the other hand, anecdotes frequently stated that receiving support, such as home care, meant adapting to caregivers' work routines and schedules, and loss of control, influence and choices, culminating in feelings of dependence and exposure (Gowing et al. 2016; Jarling et al. 2018; Krothe 1992; Moe et al. 2013; Soodeen et al. 2007; Spoorenberg et al. 2015; Tiilikainen et al. 2019; Toien et al. 2015). A female participant in the interviews of Jarling et al. (2018) reported:

I have said, no guys, when I shower... don't want to show myself when I am old. I feel ashamed. Shame, you're ashamed... for your body when it becomes old. Those who send me caregivers do not take my privacy into account (p. 4, home care).

It became clear that maintaining control and independence was a delicate balancing act. This proved once more that receiving the support they needed was crucial to older people. Receiving too little or too much support could lead to dependence, whereas the "right" amount of support, i.e., an individually adjusted program, promoted feelings of selfcontrol and independence among older people (Gowing et al. 2016; Krothe 1992; Sandberg et al. 2014). For most older persons, this was only possible at home; institutional care was perceived as a threat to their self-control and independence (Bjornsdottir 2018; Gowing et al. 2016; Jarling et al. 2018; Krothe 1992; Soodeen et al. 2007; Spoorenberg et al. 2015; van Blijswijk et al. 2018). As such, receiving appropriate information on topics such as additional services that would allow them to continue living at home and healthcare professionals who were willing to share their knowledge were important aspects of favorable healthcare (Krothe 1992; Michel et al. 2015; Modig et al. 2012; Toien et al. 2015).

In addition to this, the relationships between healthcare professionals and care receivers affected the older people's feeling of independence. A close relationship and open, confidential communication were favorable (Jarling et al. 2018; Krothe 1992; Soodeen et al. 2007). Consequently, being involved in decisions and their care helped older people to feel independent and in control, and to achieve their individual goals (Berkelmans et al. 2010; Gowing et al. 2016; Jarling et al. 2018; Krothe 1992; Modig et al. 2012; Moe et al. 2013; Sandberg et al. 2014; Schulman-Green et al. 2006; Spoorenberg et al. 2015; Tiilikainen et al. 2019; Turjamaa et al. 2014; van Blijswijk et al. 2018). Spoorenberg et al. (2015) stated:

The participants made decisions in cooperation with their case managers, which increased their sense of being in control (p. 12, population-based integrated care/case management).

This was complemented by the promotive effects of (physical, mental, social) activation via healthcare professionals (Behm et al. 2013; Krothe 1992; Martin-Matthews and Sims-Gould 2008; Spoorenberg et al. 2015; Toien et al. 2015; van Blijswijk et al. 2018).

Discussion

The aim of this review was to explore what matters to people aged 80 and over regarding ambulatory care. The meta-synthesis of 22 qualitative studies showed that three underlying wishes shape older people's perspectives: feeling safe, feeling like a meaningful human being, and maintaining control and independence.

The results are in line with previous meta-studies on the preferences and needs of older people. Dostálová et al. (2020) found six themes in fifteen studies exploring the needs of home care recipients: (1) coping with illness, (2)



autonomy, (3) relationship with professionals, (4) quality, safe and secure care, (5) role in society, and (6) environment. The authors stated that in the opinion of older people, good care also counteracts loneliness and includes casual conversations with caregivers, whereas a lack of interest in the care recipients was considered poor-quality care. While Dostálová et al. (2020) focused only on home care, this review shows that the themes are similar for ambulatory medical and nursing care in general. This might be an indication that the results truly represent the fundamental motives of the oldest old, which tend to be related to the general circumstances of their age rather than their specific care dependency. However, consequences of the perception of the older persons as meaningful individuals, by both themselves and others, seem to be more central in our review.

There are also similarities with reviews with a lower average sample age. For example, a qualitative meta-study on the needs of older people in community healthcare stressed the role of maintaining self-esteem and health (Holm et al. 2013). Two central themes were reported: (1) "reconciliation with how life has come" and (2) "desire to regain identity and sense of self-worth despite disability" (p. 6). Autonomy and the older person's sense of self were also important in studies on healthcare experiences synthesized by Gregory et al. (2017). In line with this research, our work highlights how professional care and support may be both a threat to individual independence and the key factor in the continuation of said independence. This balancing act is a neverending challenge in older age, although support needs could have been expected to be common and more accepted in this group.

This might be due to a different interpretation of "control" in older age. On this matter, Claassens et al. (2014) conducted a qualitative study to explore the concept of perceived control in healthcare among frail older adults. The authors found that the need for control did not become less important in older age, though it did take a different form. For example, the role of communication and involvement became more important to the perception of control (Claassens et al. 2014). This is in line with our findings on the significance of care relationships and care involvement to the feeling of maintaining control. The concept study also showed healthcare aspects that are able to strengthen older people's feeling of control that we also identified, such as being monitored, care coordination, and trustful relationships (Claassens et al. 2014).

Overall, our findings are similar to meta-studies on the needs and preferences of people aged 65–80, and do not show substantial differences. However, the underlying wishes that were revealed in the meta-synthesis emphasize the social dimension of care more strongly than it is found in functional care structures. This may be due to the fact that older persons need and use healthcare more frequently,

so healthcare becomes a significant part of their daily lives (Marengoni et al. 2011; van den Bussche et al. 2011; WHO 2015b). Our review shows that people aged 80 and over generally consider the incorporation of their emotional and social needs during care interactions to be integral to favorable ambulatory care. For those affected by social isolation, these aspects become even more important (Nicholson 2012).

By contrast, care models applied to older people focus mainly on assessment, care coordination and interdisciplinary treatments. Popular examples include the Chronic Care Model (CCM) and the Patient-Centered Medical Home, which are often used as basis for care interventions (Bodenheimer et al. 2002; John et al. 2020). Attempts to adopt the CCM for geriatric care, such as the Geriatric Care Model, take into account more comprehensive assessments and care coordination, which are designed specifically to cater to older people's wish to feel safe (Hoogendijk et al. 2016; Muntinga et al. 2012; Muntinga et al. 2015). However, the importance of personal care relationships and strengthening the older person as a meaningful human being do not seem to be represented sufficiently thus far and should be emphasized more strongly. Our results show that casual conversations, genuine interest in the older person, friendliness and respect promote these goals. As such, referring this demographic to other services such as social welfare, as is often proposed in existing models of care, cannot be seen as a complete solution. Instead, it could be worthwhile to focus on the health professionals' behavior and attitude toward older people and adapt care structures accordingly (e.g., by raising awareness of social needs and providing more time for care).

Strengths and limitations

To our knowledge, this is the first qualitative meta-synthesis on ambulatory healthcare needs and preferences from the genuine perspective of people aged 80 and over. The chosen search strategy enabled the consideration of a comprehensive research status, and the systematic analysis approach ensured intersubjectively valid, i.e., trustworthy and coherent results. Although the 22 included studies focused on different research questions and aspects of ambulatory healthcare, the results are mostly unambiguous, the core of the final three analytical themes emerged fast in the analysis process and further steps mainly addressed their wording and clarifications of their understanding. Therefore, we assume that the analytical themes provide a reasonable integration and explanation of the primary studies' findings and can be considered saturated in their meaning. Furthermore, the methodological quality of the individual studies was found to be sufficient according to the quality appraisal specifically encompassing trustworthiness, coherence, and



the appropriateness of the research design; this strengthens the validity of the results.

However, several limitations must be considered. Firstly, there is a possibility of dissemination bias if qualitative studies or parts of their results are not made available in full (Booth et al. 2018). The study sample is also limited by the exclusion of languages other than English, German and Dutch. Additionally, the average age of potentially eligible studies' samples was often unclear, and some authors did not respond to our requests for contact; this resulted in the exclusion of the studies in question. Despite the use of a comprehensive research strategy including an update after one year, further or contradictory research results may not have been considered.

Secondly, the findings are only applicable to developed and high-income countries, since the included studies were conducted in such countries. Primarily due to the lower average sample age, studies from low-income countries had to be excluded during screening. Since there are indications that accessibility and affordability of care are far more important issues for older people in these countries and preferences may differ depending on cultural background and known care structures, caution should be exercised if transferring the results (WHO 2015b). Further studies are needed in the countries not covered by this review, though our results could serve as a basis for their design and analysis.

Thirdly, the studies included do not represent the full range of (medical and nursing) care and services necessary to age in place. Moreover, the evidence from qualitative studies presented in this review hardly covers acute occasions for seeking ambulatory care (e.g., acute exacerbations of a chronic condition) and it is possible that older people's priorities and preferences are different in these care situations. In order to design comprehensive older-peoplecentered care, the perspective of people aged 80 and over should be researched further with regard to acute care (also in combination with chronic care) and specialties such as pharmacy and dental care.

Conclusion

This review highlights the fundamental wishes that matter to older people regarding ambulatory healthcare: feeling safe, feeling like a meaningful human being and maintaining control and independence. They interact with several aspects of ambulatory healthcare structures and care relationships that were identified as relevant. In order to achieve patient-centered care for the oldest old, future care models and policies should be developed and evaluated based on these wishes. Furthermore, the relationship between the (fulfillment of) identified wishes on patient-reported experiences and outcomes, such as well-being and satisfaction with care, should

be investigated further in order to gain a better understanding of ambulatory care favored by older people.

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Authors' contributions Angélique Herrler involved in conceptualization, methodology, formal analysis, investigation, writing—original draft, writing—review and editing, visualization, and project administration; Helena Kukla involved in formal analysis, investigation, and writing—review and editing; Vera Vennedey involved in conceptualization, methodology, and writing—review and editing; Stephanie Stock involved in conceptualization, methodology, writing—review and editing, and supervision.

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Availability of data and material All data and material is available from the authors on request.

Declarations

Conflicts of interest The authors declare that there are no conflicts of interest.

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Appendix: Publication 2

Publication 2

Which features of ambulatory healthcare are preferred by people aged 80 and over? Findings from a systematic review of qualitative studies and appraisal of confidence using GRADE-CERQual

Angélique Herrler, Helena Kukla, Vera Vennedey, Stephanie Stock

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RESEARCH ARTICLE

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Which features of ambulatory healthcare are preferred by people aged 80 and over? Findings from a systematic review of qualitative studies and appraisal of confidence using GRADE-CERQual

Angélique Herrler^{1,2*}, Helena Kukla¹, Vera Vennedey² and Stephanie Stock²

Abstract

Background: Despite healthcare providers' goal of patient-centeredness, current models for the ambulatory (i.e., outpatient) care of older people have not as yet systematically incorporated their views. Moreover, there is no systematic overview of the preferable features of ambulatory care from the perspective of people aged 80 and over. Therefore, the aim of this study was to summarize their specific wishes and preferences regarding ambulatory care from qualitative studies.

Methods: The study was based on qualitative studies identified in a prior systematic review. Firstly, the findings of the qualitative studies were meta-summarized, following Sandelowski and Barroso. Secondly, a list of preferred features of care from the perspective of older people was derived from the included studies' findings through inductive coding. Thirdly, the review findings were appraised using the GRADE-CERQual tool to determine the level of confidence in the qualitative evidence. The appraisal comprised four domains: methodological limitations, coherence, data adequacy, and data relevance. Two reviewers independently evaluated every review finding in each domain. The final appraisals were discussed and ultimately summarized for the respective review finding (high, moderate, low, or very low confidence).

Results: The 22 qualitative studies included in the systematic review were mainly conducted in Northern and Western Europe (n = 15). In total, the studies comprised a sample of 330 participants (n = 5 to n = 42) with a mean or median age of 80 and over. From the studies' findings, 23 preferred features of ambulatory care were identified. Eight features concerned care relationships (e.g., "Older people wish to receive personal attention"), and 15 features concerned healthcare structures (e.g., "Older want more time for their care"). The findings emphasized that older people wish to build strong relationships with their care providers. The majority of the review findings reached a moderate or high confidence appraisal.

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Conclusions: While the listed features of healthcare structures are common elements of care models for older people (e.g., Geriatric Care Model), aspects of care relationships are somewhat underrepresented or are not addressed explicitly at all. Future research should further explore the identified preferred features and their impact on patient and care outcomes.

Keywords: Aged, 80 and over, Patient-centered care, Ambulatory care, Qualitative research, Patient preferences, Systematic review

Background

The population of people aged 80 and over is the fastest growing age group worldwide [1]. It is frequently said that healthcare systems are not adequately prepared for this demographic change [2-5]. The biggest challenge described in most research and policy papers is the increasing burden of disease due to chronic diseases, multimorbidity, frailty and disability [2, 4, 6–9]. However, most healthcare systems are still characterized by fragmented care and an orientation toward acute care [4, 10-12]. It is argued that these preconditions result in inadequate treatments and deteriorations in patient health, and therefore lead to more frequent use of services and rising costs [2, 4, 9, 13]. Although the use of services and rising costs not only affect ambulatory (i.e., outpatient) care, this area has a particular importance since ageing in place and the prevention of institutionalisation are important personal and political goals [5].

As a result, several concepts and models, especially for ambulatory healthcare, have been developed. The most popular approaches and propositions are integrated care and improved sharing of information, interdisciplinary teamwork, the redesign of healthcare workers' roles, and coordinated care and case management, as well as (geriatric) assessments [2, 3, 7, 8, 10, 12, 14–17]. Moreover, the empowerment of the patient, and the discussion of needs and goals, as well as prevention and health promotion, are required [2, 3, 12]. Most ambulatory care models designed for older people therefore incorporate these aspects (e. g., Geriatric Care Model [18], GRACE [19], Guided Care Model [20], Embrace [21]).

While patient empowerment and autonomy are now frequently described goals of these models, it is surprising that most did not systematically incorporate older patients themselves in their development. Therefore, the features chosen mainly represent the professional (medical) perspective and not necessarily what is important to older people. This applies particularly to those aged 80 and over, since the common models mainly address age groups starting at around 65 years. By contrast, to achieve patient-centred care, which has been claimed as the overarching aim in the design of healthcare, the values, preferences and needs of the patients should be evaluated and put centre stage [5, 22].

In a recent systematic review and meta-synthesis of 22 qualitative studies, we identified three basic needs of people aged 80 and over regarding ambulatory care: feeling safe; feeling like a meaningful human being; and maintaining control and independence [23]. While these findings explain older people's general view of ambulatory healthcare, the studies also provide several direct descriptions of specific features which could have tangible implications for practice and the design of healthcare. However, there has been no systematic overview of the genuine perspectives of people aged 80 and over regarding the preferable features of the design of ambulatory care. Therefore, we aimed to re-analyze the findings of the primary studies in order to answer the question: What are the specific preferences and wishes of older people regarding favorable aspects of ambulatory healthcare? By "preferences," we mean "what patients want from their healthcare" ([24], p. 168).

Methods

Data basis

We conducted a secondary analysis and appraisal of confidence in review findings based on qualitative studies from a previous systematic review of the question: What matters to older people regarding their ambulatory care? [23]. The review incorporated a comprehensive database search in Web of Science Core Collection, Medline, PsycINFO and CINAHL, which was complemented by a keyword search in Google Scholar, as well as by a forward and backward citation search. Qualitative primary study reports exploring the subjective preferences, wishes, needs and experiences of people aged 80 and over in ambulatory healthcare settings, performed by professionals, were included. The search covered full research reports published in English, Dutch and German from inception to October 2020, and led to 5576 potentially relevant research reports. Their titles, abstracts and full texts were screened against the eligibility criteria by two independent reviewers, who agreed to include 23 research reports. After independently appraising the quality of the studies, 22 reports were finally included. Further details on the search and selection process are reported elsewhere [23]. Reporting in this paper is based

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on the recommendations of Tong et al. for qualitative syntheses (ENTREQ) [25].

Analysis

While the aim of the original review was to integrate the findings of the primary studies and, consequently, provide a new interpretation of them, the present analysis focuses on the extraction and condensation of specific preferable features of healthcare. Moreover, we were interested in the features' trustworthiness for use in evidence-based practice. Therefore, we started with an aggregation of the 22 studies identified using the meta-summary approach. According to Sandelowski and Barroso, a meta-summary comprises several steps: extracting data, clustering data and abstracting findings [26]. Firstly, the qualitative results that explicitly referred to the older people's perspective were extracted (mainly from the "findings" section of the study reports) and transferred to MAXQDA Analytics Pro 2020 for analysis (Verbi software, Berlin). Secondly, two authors (AH, HK) independently coded the findings of the studies line-by-line, clustered them around different aspects of healthcare (e.g., "access"), and discussed their results until a consensus was reached. Thirdly, the first author condensed the contents of the clusters around specific features of ambulatory care. The results were discussed by the research team. Their extent was iteratively refined, and clear statements on the desirability of the care feature (e.g., "older people accept/ reject/prefer (...)") were formulated.

Appraisal of confidence in the evidence

In the subsequent step, the review findings were examined in terms of their informative value and trustworthiness. In the past, this was often done by calculating the frequencies of the qualitative findings [26]. Since this approach follows a quantitative logic and is therefore not ideal for qualitative research, we decided to conduct a detailed confidence appraisal using the relatively new GRADE CERQual tool ("Confidence in the Evidence from Reviews of Qualitative Research") [27, 28]. CER-Qual is used to appraise each review finding in four different domains: methodological limitations; coherence; data adequacy; and data relevance [28]. The assessment of methodological limitations was based on the quality appraisal of each included study using the qualitative studies checklist issued by the National Institute for Health and Care Excellence [29]. For each review finding, the quality appraisals of the studies contributing to the respective finding were afterwards summarized and checked for important limitations, e.g., in study design or data analysis [30] (Additional file 1). Coherence was assessed as the fit between the original data and the resulting review finding [31]. Each review finding was compared with all original text segments that it was based on and with the themes developed in the contributing studies. Contradictory data, alternative descriptions or explanations, and unclear data support were considered for rating coherence [31] (Additional file 2). Data adequacy was assessed similarly, but with a focus on data richness and quantity in order to explore the validity and explanatory power of the respective review finding [32] (Additional file 2). Data relevance was assessed as the fit between the review question and the context of included studies. For each review finding, the studies contributing to it were checked for the population, setting and phenomenon of interest (Additional file 3). Two authors (AH, HK) independently assessed each domain per review finding and rated it (no or very minor concerns; minor concerns; moderate concerns; or serious concerns). The ratings were discussed until a consensus was reached; a third author (VV) was consulted, where necessary.

Finally, a CERQual qualitative evidence profile for every review finding evolved in which each received an appraisal for every domain. The final appraisals of the four domains were discussed by the research team and ultimately summarized for the respective review finding [28]:

- "High confidence: It is highly likely that the review finding is a reasonable representation of the phenomenon of interest.
- *Moderate confidence*: It is likely that the review finding is a reasonable representation of the phenomenon of interest.
- Low confidence: It is possible that the review finding is a reasonable representation of the phenomenon of interest.
- Very low confidence: It is not clear whether the review finding is a reasonable representation of the phenomenon of interest" [27, p. 6].

Results

The 22 qualitative studies that served as a basis were mainly conducted in Northern and Western Europe and in total comprised 330 participants who lived at home. The participants were mainly multimorbid or frail, and showed a broad range of chronic conditions. The care settings examined were 1) general or specialist ambulatory healthcare (nine studies), 2) home care/community-based long-term care (seven studies), 3) case management (three studies) and 4) home visits (three studies). There were three studies that conducted focus groups or group interviews, all the other studies

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conducted individual or couple interviews. An overview on the studies is provided in Table 1.

From these 22 studies, our analysis resulted in 23 review findings on the preferable features of ambulatory care. The majority of them reached moderate or high confidence. Fifteen review findings concerned the structures of healthcare and eight review findings concerned care relationships. In the following section, each review finding will be presented with a short description to provide a better understanding of its meaning. Table 2 summarizes the findings, together with their overall CERQual rating and examples for supporting data. The CERQual qualitative evidence profile (Additional file 4) provides an overview of the assessments and explanations for each appraisal domain. To provide a better understanding of the findings' applicability, Figs. 1, 2 and 3 show the review findings in relation to the examined care settings of the contributing studies.

Review findings with high appraisal of confidence Older people wish to receive care that fits their individual needs

For older people, one remarkable feature was that they wanted to receive holistic care, sufficient support that met their needs and supported their independence, and individual adjustments to care and care planning [34–38, 40–43, 45, 46, 48–50, 53]. Concomitantly, older people negatively judged experiences such as not receiving the care needed (regarding lack of time, money, personnel or individual attention), not receiving individual adjustments to care, not been taken seriously with their concerns, and a focus on acute problems and symptoms instead of a long-term perspective and goal setting [35, 37, 38, 40–42, 44, 45, 47, 50].

Older people value being looked after regularly

The older people highly appreciated having a healthcare professional who "kept an eye" on them. They felt reassured when someone monitored their health status, looked after them regularly, cared for chronic issues (e.g., wounds, medications) and could intervene fast, if necessary [35–37, 41, 43, 46, 48–50, 53]. However, a specific frequency or contact interval was not proposed.

Older people want fast contact to care

It became apparent that older people wish to make contact with a (known) healthcare professional fast, if needed. They prefer to have a constant person or healthcare practice which they could contact if advice or help was required [33, 34, 42, 46, 48]. Widespread and fast availability via phone was especially valued [34, 37, 41, 42, 48, 50].

Older people want easy access to care

Most participants in the qualitative studies had already experienced difficulties or restrictions in accessing healthcare, e.g., for specialist services. Although some of them mentioned that the proximity of services was good, widespread access to healthcare, including on weekends and on an intermittent basis, as well as easily accessible follow-up services and referrals, were rated most important [34, 35, 38, 41, 46, 47, 50, 52]. Older people identified restricted opening hours, the fragmented nature of the care systems, and the need to go through several levels of care before receiving the right treatment as barriers to good access [38, 46, 47, 49, 50, 52].

Older people want reliable and continuous care

Older people frequently reported a high turnover of healthcare professionals responsible for them but strongly desired continuity. They wanted their caregivers to know them personally and to have a good overview of their living circumstances and care needs [34, 37–39, 41–43, 45–47, 49–51, 54]. A lack of continuity led to stress, unstructured and impersonal care, insecurity and information loss [38, 39, 41, 42, 49, 54]. Furthermore, they wanted reliability in receiving care, e.g., a regular schedule and predictability [35, 39, 48, 54].

Older people prefer home care

Consistently, study participants expressed a strong desire to stay in their own homes for as long as possible because of the better quality of life, increased privacy and control, and the belief that their homes offered a more secure environment [33, 35, 37, 38, 45, 46, 50, 54]. They acknowledged that receiving home care and support was needed for them to age in place [35, 38, 45, 46, 49]. There were indications that, in contrast, a nursing home would constitute a threat to older people's personal integrity and quality of life; they had quite a negative view of institutional care [38, 46]. Seldom was institutional care perceived as the better option to meet their needs [37].

Older people value advice to help with daily life

Several studies found that older people value receiving advice to help with their daily lives. They welcomed practical advice for adaptations of their home (e.g., the removal of carpets to prevent falls), safety information and education regarding health issue prevention and diet, and recommendations for exercises [33, 35, 40, 43, 46, 48, 53].

Older people want more time for their care

A major obstacle to favorable care was time constraints. Participants described that their care or medical

Table 1 Overview of studies				
Study	Aim	Inclusion criteria/Sample	Setting ^a	Themes
Behm et al. 2013 [33] Sweden	Description of older people's experiences of a preventive home visit and meaning for (future) health	N=17 participants aged 80 or older who live at home, are cognitively intact and are independent of help, recruited via "Elderly persons in the risk zone" intervention (seven men, twelve women)	Home visits	• The preventive home visit (PHV) made me visible and proved my human value • The PHV brought a feeling of security • The PHV gave an incentive to action • The PHV was not for me
Berkelmans et al. 2010 [34] Netherlands	Description of non-medical service and product attributes older people value in GP care	N=13 participants (mean age 81.2 years), recruited via four GP prac- tices (six men, seven women)	Ambulatory general practice or specialist care	Continuity of caregiver Distance to the practice Accessibility Expertise and trust Attitude Information Pro-active Initiatives Waiting time in the waiting room Free choice of GP
Bjornsdottir 2018 [35] Iceland	Understanding of the nature of home care nursing practice	N=15 home care nursing clients aged 80 or over, identified as frail, recruited via home care nurses (six men, nine women)	Home care and community-based long-term care	 The world at home Relating to an ailing body and treatments Give-and-take – life in relations Home care services as world making
Faeo et al. 2020 [36] Norway	Description of experiences and attitudes of home-dwelling persons with dementia regarding assistive technology, volunteer support, home care services and day care centers	N=12 participants aged 65 and over (mean age 82 years) with a registered dementia diagnosis who live at home, recruited via four daycare centers (six men, six women)	Ambulatory general practice or specialist care	 (Assistive technology – safety with side effects) (Volunteer support – the complexity of preferences) Home care services – the diversity of car experience Daycare centers – it's all in the details
Gowing et al. 2016 [37] UK	Exploration of views and experiences of patients and carers regarding a case management programme	N=16 older participants (median age 82.5 years) enrolled in the Northumberland High Risk Patient Programme who live at home and do not receive palliative care, recruited via 11 GP practices (five men, eleven women) (N=7 family members)	Case management	 Awareness and understanding of the NHRPP Confidence in the primary healthcare team Limitations of home care The active role of being a patient
Jarling et al. 2017 Sweden	Description of meaning of home care from the perspective of multimorbid older people	N=12 home care clients aged 75 or older (77–90 years) with multimorbidity who live alone, recruited via the municipality's contact person (four men, eight women)	Home care and community-based long-term care	• Becoming a guest in your own home • Adapting to a caring culture • Feeling exposed • Unable to influence care • Forced relations

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Study	Aim	Inclusion criteria/Sample	Setting ^a	Themes
King et al. 2017 New Zealand	Description of experiences of older people and health professionals regarding a primary healthcare gerontology nurse specialist role	N=5 participants aged 75 and older (mean age > 80 years) who received the intervention, recruited via primary healthcare practices (selection from a random numbers table; two men, three women) (N=6 healthcare professionals)	Case management	Holistic expertise Communication (Competency) (Service delivery)
Krothe 1992 [38] USA	Description of community-based services needed by older people to avoid institutionalization	N=9 clients of an Area Agency on Ageing (mean age 81.4 years), recruited via the agency's case man- ager (two men, seven women)	Home care and community-based long-term care	Maintaining control Goal setting The nursing home Role of family Essential formal services Informal help/assistive devices Significance of home and possessions Day to day activities/community connectedness Finding out about CB-LTC and assisted living Future needs for CB-LTC and assisted living Significance of past experience Significance Spirituality Listening for individualized needs Some elderly people are like that Being alone and loneliness
Martin-Matthews & Sims-Gould 2008 [39] Canada	Description of salient home support services issues from the perspective of employers, home support workers and clients	 N=14 home care clients (mean age 83 years), recruited via home support agencies (four men, ten women) (N=11 home care employers and n=32 home support workers) 	Home care and community-based long-term care	(Recruitment and retention) (Increasing complexity of client needs) • (Acknowledgement of the needs and desires of clients) • (Appropriateness of home support as part of the healthcare continuum) • (Scheduling and time demand) • (Tension in providing intimate ongoing care at an emotional distance) • (Balance between tasks outlined in the care plan and the needs and wants of elderly clients) • Ongoing need to prepare for and manage service • Desire and need for companionship

Table 1 (continued)				
Study	Aim	Inclusion criteria/Sample	Setting ^a	Themes
Michel et al. 2015 [40] Brazil	Analysis of similarities and dissimilarities in the meanings assigned to healthcare by older people and nursing professionals	N = 10 participants aged 80 and over who were users of the basic health unit for at least six months (five men, five women) (N=10 nursing professionals)	Ambulatory general practice or specialist care	• "Because we are older": reasons to provide health care to long-lived elders • "Being well served" and more help at home: attributes of health care for long-lived elders • Health services and practices that do good: used to provide health care to long-lived elders • (Old age and vulnerability: reasons to provide health care to long-lived elders) • (Deficits in proper care: attributes of health care for long-lives elders) • (Responsibility of families and guidance: used to provide health care to long-lives elders)
Modig et al. 2012 [41] Sweden	Description of frail older people's experiences regarding information about their medications	N=12 participants aged 65 and older (median age 80.5 years), needing help with two or more ADL, who were admitted to hospital twice or more, had at least four outpatient contacts in the prior twelve months, and received cardiovascular medication; recruited via a case manager intervention study (five men, seven women)	Ambulatory general practice or specialist care	Comfortable with information Insecure with information
Moe et al. 2013 [42] Norway	Description of the meaning of receiving home nursing care for chronically ill older people living at home	N=11 participants aged 80 and over, living at home with chronic conditions, and receiving home nursing care (five men, six women)	Home care and community-based long-term care	 Being ill and dependent on help Being at the mercy of help Feeling inferior as human being
Sandberg et al. 2014 [43] Sweden	Description of frail older people's and case management intervention management contains and management intervention	N=14 participants aged 65 or older (mean age 83 years) who received the intervention, lived in an ordinary home, needed help for at least two ADL, were admitted to hospital at least twice and had for outpatient care contacts in the prior twelve months; recruited via one university hospital, four primary care centers, the municipal home care organization (four men, ten women)	Case management	• The case manager as a helping hand • Case management as a possible additional resource • (The case manager as a coaching guard) • (Case management as entering a new professional role)

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Study	Aim	Inclusion criteria/Sample	Setting ^a	Themes
Schulman-Green et al. 2006 [44] USA	Description of older adults' interaction regarding their life and health goals during the clinical encounter	N=42 participants aged 60 or over (mean age 81 years) living in a high-income independent living facility, a subsidized assisted living facility or a private condominium complex, identified by a contact person for each residential site (15 men, 25 women) (N=11 clinicians)	Ambulatory general practice or specialist care	Not a priority given limited time Focus on symptoms Clinician-patient mutual perception of disinterest in goal setting Presumption that all patients' goals are the same
Soodeen et al. 2007 [45] Canada	Description of home care experiences of physically impaired older people and their spouses	N=9 home care receivers (mean age 80 years) with at least one ADL or IADL and one chronic condition, recruited via newspaper a article, referrals from seniors housing complexes and the staff of church-run programs (three men, six women) (N=9 spouses)	Home care and community-based long-term care	• Independence • Developing a trusting relationship with home care workers • (Relief) • (Continuity)
Spoorenberg et al. 2015 [46] Netherlands	Description of older adults' perspective regarding integrated care and support	N=23 participants of the intervention (mean age 82 years); frail people or those with complex care needs were recruited by their case managers; robust people were recruited by project managers (ten men, 13 women)	Ambulatory general practice or specialist care	• Experiences with aging • Struggling with health • Increasing dependency • Decreasing social interaction • Loss of control • Faers • Experiences with Embrace • Relationship with the case manager • Interactions • Feeling in control, safe and secure
Tiilikainen et al. 2019 [47] Finland	Description of older people's perceptions of quality of life from the perspective of access and use of health and social care services	N=19 participants who lived alone (mean age 80 years) and received health and social services during the past six months, recruited via local health and social service professionals (four men, 15 women)	Ambulatory general practice or specialist care	• Access to services and information • Recognition inside the services
Toien et al. 2015 [48] Norway	Description of older people's perspectives regarding preventive home visits	N=10 participants (mean age 85.5 years) who had at least six years of experience with the preventive home visits service and with various characteristics, recruited via a municipal health care service nurse (four men, 6 women)	Home visits	• To feel safe • To manage daily life • To live well • To be somebody
Turjamaa et al. 2014 [49] Finland	Description of older people's and practical nurses' perspectives regarding available home care and enablers for continuity of living home	N=23 home care clients aged 75 or older (mean age 84 years) with at least one or two home visits a day, recruited via practical nurses (N=14 practical nurses)	Home care and community-based long-term care	 Organisationally driven care Individual encountering the multifaceted system

Table 1 (continued)

Study	Aim	Inclusion criteria/Sample	Setting ^a	Themes
van Blijswijk et al. 2018 [50] Netherlands	Description of older people's experiences regarding hindering health complaints, how they deal with them and what they expect from their GP	N=24 participants aged 80 or older with pain and/or problems with walking/standing, recruited via an integrated care trial (six men, 18 women)	Ambulatory general practice or specialist care	Health complaints and impact Self-management of health complaints and limitations Expectations of their GP concerning their health complaints Shared decision-making Pro-active care Attentive care: support and empathy Attainability and accessibility Coordinating health care and medication
van Kempen et al. 2012 [51] Neth- erlands	Description of frail older people's views and needs regarding home visits	N=11 frail patients aged 65 or over (median age 80 years, two men, nine women) (N=11 informal caregivers)	Home visits	• The need for home visits • Preferences for home visits
Walker et al. 2018 [52] Australia	Description of older dementia patients' and their family caregivers' experiences and preferences regarding dementia assessment services	N=9 participants aged 65 or older (mean age 80 years) with a formal diagnosis of mild dementia within the prior three months, recruited via a geriatrics service and an Alzheimer's Association (five men, four women) (N=7 caregivers)	Ambulatory general practice or specialist care	Being "handled" properly: facilitators and barriers to a formal diagnosis Perceptions on length of time between diagnosis and accessing support services Preferences for diagnostic service settings: importance of avoiding stigma

In some studies, additional participant groups, such as caregivers were included and some of the primary studies results apply only to them. In our analysis, we included only findings that explicitly referred to our target group. However, other groups and results of the primary studies are reported in parentheses to enhance transparency

^a The studies were assigned to four different contexts: 1) ambulatory general or specialist healthcare, 2) home care/community based long-term care, 3) case management, 4) home visits

GP General practitioner/practice, ADL Activities of daily living, IADL Instrumental activities of daily living, CB-LTC Community-based long-term care

Summary of review finding	Contributing studies	Example for data support (original citations from the qualitative studies' participants)	CERQual assessment of confidence	Explanation of CERQual assessment
Features of healthcare structures 1. Older people wish to receive care that [34–38, 40–50, 53] fits their individual needs	[34–38, 40–50, 53]	"It is what they do – they who are the right persons they do something extra. They have learned to treat us as we want" ([42], p.742)	High	Seventeen studies with no or very minor concerns regarding methodological limitations and adequacy contributed to this review finding. Although there were minor concerns about coherence and relevance, this was only due to a limited number of studies/extent of data
2. Older people value being looked after regularly	[35–37, 41, 43, 46, 48–50, 53]	"The most important is the safety – you know, that someone cares and looks after you and checks that the head is still functioning; that is very reassuring. And knowing you are within the municipality's system" ([48], p. 704)	High	Ten studies with no or very minor concerns regarding adequacy and relevance contributed to this review finding. Although there were minor concerns about methodological limitations and coherence, this was only due to a limited number of studies/extent of data
3. Older people accept delegation	[34, 37, 47, 50, 51]	"Or he'll send the head nurse to see what's the matter. One of them would be here and see exactly what's the matter and she would confer with him [the GP] what was to be done" ([37], p. 4)	Low	Five studies contributed to this review finding. While there were no or very minor concerns regarding methodological limitations, there were moderate concerns regarding coherence and adequacy because of the small number of studies and partially contradictory data. Moreover, there were minor concerns about relevance
4. Older people value home visits, but not all think they are necessary	[33, 34, 50, 51]	"The GP can go through his patient records to see which patients need a home visit, which patients really need it" ([51], p. e557)	Low	Four studies contributed to this review finding. While there were no or very minor concerns regarding methodological limitations and relevance, there were moderate concerns regarding coherence and adequacy because of the small number of studies and partially contradictory data
5. Older people want fast contact to care	[33, 34, 37, 41, 42, 46, 48, 50]	"know who to call, and I am certain that I will get help the day I need. It cannot be any better" ([48], p. 704)	High	Eight studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
6. Older people want easy access to care [34, 35, 38, 41, 46, 47, 49, 50, 52, 53]	[34, 35, 38, 41, 46, 47, 49, 50, 52, 53]	"It goes through so many different levels before you actually get any help []. If you need them, they're not there"([46], p. 9)	High	Ten studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations, coherence and adequacy. Although there were moderate concerns regarding relevance, the review finding still is a valid representation of the data

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Summary of review finding	Contributing studies	Example for data support (original citations from the qualitative studies' participants)	CERQual assessment of confidence	Explanation of CERQual assessment
7. Older people reject waiting times	[34, 35, 41, 54]	"I come here for an appointment and wait for three hours. There is no single time I have come here when my blood pressure hasn't gotten higher, I guess I get angry. Where is the priority on old age? At least above 80 years old. I'm 87" ([40] p. 346)	Moderate	Four studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations and coherence. However, there were minor concerns regarding adequacy and relevance and due to the quite small number of studies, we found that this weakened the review finding
8. Older people want reliable and continuous care	[34, 35, 38, 39, 41-43, 45-47, 49-51, 54]	"Never the same [nurse]. Do not know how many different persons they are? I do not know who is coming you know" ([42], p. 740)	High	Fourteen studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations, coherence and adequacy. Although there were minor concerns regarding relevance, there was in sum no negative impact on the review finding
9. Older people value care coordination	[37–39,41,43,46,48–50,53]	"She was wonderful, she was a wonderful help she sorted my doctor out, and sorted my nurse out" ([53], p. 811)	Moderate	Ten studies contributed to this review finding. There were no or very minor concerns regarding coherence and adequacy. However, there were moderate concerns regarding methodological limitations and relevance that weakened the review finding in total
10. Older people prefer home care	[33, 35, 37, 38, 45, 46, 49, 50, 54]	"You feel best at home, this is your home, where your things are. The home is part of you. Being at home means that everything is friendly and free" ([35], p. 3)	High	Nine studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations and adequacy. Although there were minor concerns regarding coherence and relevance, this did not significantly affect the review finding, which was still a valid representation of the data
11. Older people prefer personal information	[33, 34, 41, 47, 50]	"Well, I think you absorb better, you understand it better, what's available. Otherwise I think that we would just have thrown away the brochures and thought that we would wait to deal with it until something happens. Now we know about this, we have received a visit, it remains in our memory" ([33], p. 5)	Low	Five studies contributed to this review finding. While there were no or very minor concerns regarding methodological limitations, there were moderate concerns regarding relevance. Moreover, there were minor concerns regarding coherence and adequacy. Since the number of contributing studies was small, we found that this significantly impacted the strength of the review finding

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Summary of review finding	Contributing studies	Example for data support (original citations from the qualitative studies' participants)	CERQual assessment of confidence	Explanation of CERQual assessment
12. Older people value advice to help with daily life	[33, 35, 40, 43, 46, 48, 53]	"And I find it very difficult to keep my balance. And they Iname, physiotherapist in the project] asked me how would it be if you stood with your legs further apart then your balance will be a bit better And I've been doing it, and it's absolutely true, because now I can stand and wash up" ([43], p. 9)	High	Seven studies contributed to this review finding. There were no or very minor concerns regarding coherence, adequacy and relevance. However, there were moderate concerns regarding methodological limitations. Since this is mostly due to one study, there was no significant impact on the review finding in total
13. Older people want information on care options and services	[33, 38, 43, 47, 48, 50]	"She understands my problems and has suggested a number of assistive devices that I neither knew existed nor knew that I could get. I could not have managed without those helping aids. Thanks to them, I can now live close to normal" ([48], p. 705)	Moderate	Six studies contributed to this review finding. While there were no or very minor concerns regarding methodological limitations, there were minor concerns regarding coherence and adequacy. Moreover, there were moderate concerns regarding relevance that weakened the review finding
14. Older people want to be informed comprehensively	[33–35, 38, 41–43, 52]	"When I get a new pill, she usually goes through it with me; she usually says what it is good for and how it works and such things. And I should watch if I have something more than what is written in the leaflet. If something else happens" ([41], p. 5)	Low	Eight studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations. However, there were moderate concerns regarding coherence, adequacy and relevance. Since there was one study with limitations that provided a large part of data and moreover, there were partially contradictory data, there was a strong weakening of the review finding
15. Older people want more time for their care	[34, 36, 37, 41, 42, 44, 47, 49–51, 53]	"I just wish the GP would listen to me for a while. Just sit there and listen to me and give me my say I think just let me try and explain things to you. But he's a very busy man" ([53], p. 812)	High	Thirteen studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations, coherence, adequacy and relevance. Although there were minor concerns regarding relevance, this did not impact the strength of the review finding
16. Older people expect healthcare professionals to be knowledgeable	[34, 37, 38, 41–45, 48, 50, 52, 53]	"I also expect him to keep his level of knowledge up to par with his skills. By which I mean, that he takes refresher courses regularly" ([34], p. 4)	High	Twelve studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations, coherence and adequacy. Although there were moderate concerns regarding relevance, the review finding was still a valid representation of the data

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Table 2 (continued)				
Summary of review finding	Contributing studies	Example for data support (original citations from the qualitative studies' participants)	CERQual assessment of confidence	Explanation of CERQual assessment
17. Older people value healthcare pro- fessionals' communication skills	[43, 45, 46, 48, 50, 52, 53]	"She explained everything so well that made a difference" ([53], p. 810)	Moderate	Seven studies contributed to this review finding. There were no or very minor concerns regarding coherence and relevance. However, there were minor concerns regarding adequacy and moderate concerns regarding methodological limitations. Altogether, we found that this weakened the review finding, but to a limited extent
18. Older people wish to receive personal attention	[33–36, 38–40, 42, 43, 45–49, 53, 54]	"Just that they think about us, it's nice, they think of older people" ([33], p. 4)	High	Sixteen studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
19. Older people value close, long-term relationships	[34, 35, 38–40, 42, 43, 45, 49, 51, 53, 54]	"They have become my friends, and I can rely on them" ([35], p. 5)	High	Twelve studies contributed to this review finding. There were no or very minor concerns regarding coherence, adequacy and relevance. Although there were minor concerns regarding methodological limitations, this was only due to a small number of studies and there was no impact on the review finding in total
20. Older people want to be treated in a friendly way	[34-36, 40, 42, 43, 45, 47, 48, 53, 54]	"I want them to be honest and also I want them to be friendly" ([45], p. 1249)	High	Eleven studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations, coherence and adequacy. Although there were minor concerns regarding relevance, this was only due to a small number of studies and there was no impact on the review finding in total
21. Older people value open and confidential communication	[34, 38, 41–43, 45, 46, 48–51, 53, 54]	"And you could talk to her about everything. About things I do not want to mention to you. But I developed very good trust to her" ([43], p. 9)	High	Thirteen studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
22. Older people want to be involved in decisions and care	[34, 35, 37–39, 41, 42, 44–47, 49–51, 53, 54]	"Once I had an infection in my wrist and that was solved—but he's never asked about it again. That's a little bit of response you would like to receive, that you feel that we've solved the problem together" ([50], p. 9)	Moderate	Sixteen studies contributed to this review finding. There were no or minor concerns regarding adequacy, but minor concerns regarding methodological limitations, coherence and relevance. In total, we found that the review finding lost strength, in particular due to contradictory data

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Table 2

Summary of review finding	Contributing studies	Example for data support (original citations from the qualitative studies' participants)	CERQual assessment of confidence	Explanation of CERQual assessment
23. Older people value activity	[33, 36–39, 42, 43, 46, 48–50, 52]	"Now you are old, but look how much you High can do, and it's me who will do it. It's not them, it's me who will do all the things they talked about. I need to engage in all these activities, I cannot just sit I have an insight, an insight into everything that I can do now and that feels very important" ([33], p. 5)	High	Twelve studies contributed to this review finding. There were no or very minor concerns regarding methodological limitations, coherence, adequacy and relevance

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	Review finding	Α	mbul	atory		al/sp (n = 9)		t heal	thcare	Hoi	me ca		nmun care (sed lo	ng-		CM (n= 3)		me visit: (n = 3)
	Older people wish to receive care that fits their individual needs.	34	36	40	41	44	46	47	50	35	38	42	45	49			37	43	53	48	
	Older people value being looked after regularly.	36	41	46	50					35	49						37	43	53	48	
	Older people want fast contact to care.	34	41	46	50					42							37			33	48
	Older people want easy access to care.	34	41	46	47	50	52			35	38	49					53				
	Older people want reliable and continuous care.	34	41	46	47	50				35	38	39	42	45	49	54	43			51	
High Confidence	Older people prefer home care.	46	50							35	38	45	49	54			37			33	
	Older people value advice to help with daily life.	40	46							35							43	53		33	48
	Older people want more time for their care.	34	36	41	44	47	50			42	49						37	53		51	
	Older people expect healthcare professionals to be knowledgeable.	34	41	44	50	52				38	42	45					37	43	53	48	
	Older people wish to receive personal attention.	34	36	40	46	47				35	38	39	42	45	49	54	43	53		33	48
	Older people value close, long-term relationships.	34	40							35	38	39	42	45	49	54	43	53		51	
	Older people want to be treated in a friendly way.	34	36	40	47					35	42	45	54				43	53		48	
	Older people value open and confidential communication.	34	41	46	50					38	42	45	49	54			43	53		48	51
	Older people value activity.	36	46	50	52					38	39	42	49				37	43		33	48

Fig. 1 Review findings with high appraisal of confidence and care contexts of the contributing studies. Note: The numbers in the row are the references of the studies contributing to the respective review finding, sorted by their care contexts. n, total number of studies included from the respective care context

appointments were frequently rushed and that there was not enough time for the necessary help and conversation [34, 36, 37, 41, 42, 44, 47, 49–51, 53]. Insufficient time for care was described as resulting in unresolved questions and a focus on acute tasks and symptoms, rather than on considering long-term plans and goals [36, 37, 41, 44, 47].

Older people expect healthcare professionals to be knowledgeable

The older people expected healthcare professionals to have a certain level of knowledge and experience in order to provide good care, which was also described as a condition for trust [34, 37, 38, 41–45, 48, 50, 52, 53].

Older people wish to receive personal attention

Descriptions of care as an important social contact point were relevant in almost all studies, but more frequently in those describing home care and home visits. The interviewees appreciated having the feeling that someone was interested and cared about them [33, 34, 38, 40, 46, 53]. In several studies, it was indicated that

the social aspects of care — caregivers spending time with them, starting conversations, providing emotional support — were highly valuable for the older persons' well-being [33, 36, 38, 39, 42, 43, 45–49, 53, 54]. The older people also revealed this wish for beneficial contacts in describing negative experiences, e.g., caregivers visibly hurrying, not talking and not focusing on them, which resulted in negative feelings and a sense of isolation [35, 38, 42, 45–47].

Older people value close, long-term relationships

Establishing close, long-term care relationships was an overall present topic, although mainly related to home care professionals (e.g., nurses) or case managers. Older people wanted trustful interactions with well-known healthcare professionals that enabled them to share personal issues and to feel safe and strengthened [34, 35, 38, 40, 42, 43, 45, 49, 51, 53, 54]. Frequently, it was indicated that they developed friendships or family-like relationships [35, 39, 42, 43, 45, 53, 54].

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	Review finding	ρ	mbula	atory	-	al/spe n = 9)		t healthcare	Hoi	ne ca		nmun care (ong-		CM (n= 3))		me visits (n = 3)
	Older people reject waiting times.	34	41						35	54						37	43	53	48	
dence	Older people value care coordination.	41	46	50					38	39	49					37	43	53	48	
ate Confi	Older people want information on care options and services.	47	50						38							43			33	48
Moder	Older people value healthcare professionals' communication skills.	46	50	52					45							43	53		48	
	Older people want to be involved in decisions and care.	34	41	44	46	47	50		35	38	39	42	45	49	54	37	53		51	

Fig. 2 Review findings with moderate appraisal of confidence and care contexts of the contributing studies. Note: The numbers in the row are the references of the studies contributing to the respective review finding, sorted by their care contexts. n, total number of studies included from the respective care context

	Review finding	Д	mbul	atory	general/specialist healthcare (n = 9)	Home care/community-based long- term care (n= 7)		CM (n= 3)		me visits n = 3)
	Older people accept delegation.	34	47	50			37		51	
Confidence	Older people value home visits, but not all think they are necessary.	34	50						33	51
Low Con	Older people prefer personal information.	34	41	47	50				33	
	Older people want to be informed comprehensively.	34	41	52		35 38 42	43		33	

Fig. 3 Review findings with low appraisal of confidence and care contexts of the contributing studies. Note: The numbers in the row are the references of the studies contributing to the respective review finding, sorted by their care contexts. n, total number of studies included from the respective care context

Older people want to be treated in a friendly way

Older people valued a kind, open and positive attitude on the part of caregivers and wanted to be treated respectfully [34, 36, 40, 42, 43, 45, 47, 48, 53]. On the other hand, some studies described how older people felt hurt when caregivers were authoritative, disrespectful, impersonal, rude or – in general – lacked empathy [35, 42, 47, 54].

Older people value open and confidential communication

Older people would like to communicate with their care providers in an open and confidential manner. The importance of trust, genuine interest and attention to the person's broader health concerns and living circumstances were stressed, as well as the possibility of discussing everything with the professionals [34, 43, 45, 46, 48–51, 53, 54]. Concomitantly, the studies' participants described negative experiences, such as professionals not listening to them, not having the chance to speak about personal problems, and feelings of distrust, shame or being a burden, which resulted in inhibited communication [38, 41, 42, 50, 54].

Older people value activity

Several participants expressed the wish to remain as active as possible, e.g., regarding physical activity, volunteer work or social activities. They appreciated care professionals who supported them doing so [38, 42, 43, 46, 48, 50]. Furthermore, the older persons found it highly valuable when care professionals motivated them to improve their health and living circumstances, opened up a new, positive perspective of their possibilities and encouraged them to take on active roles [33, 36, 37, 39, 43, 46, 48, 49, 52].

Review findings with moderate appraisal of confidence Older people reject waiting times

The older participants found waiting times (waiting for telephone contact, waiting for an appointment, waiting at an appointment) generally problematic [34, 35, 40, 41, 54]. Some explained that their issues were urgent and priority should be given to old age; inconvenience, such as hard benches in waiting rooms, was also mentioned in connection with waiting times [34, 40].

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Older people value care coordination

Older people greatly appreciated care coordination, including in the form of case management. They felt reassured when their care services, treatments, collaboration between different providers and necessary adaptations were organized and managed by a healthcare professional, someone who had an overview and was able to provide them with additional support, where needed [37–39, 41, 43, 46, 48–50, 53].

Older people want information on care options and services

The studies' participants wanted to receive information on care options, services and additional help, in terms of which were suitable and available for them, where they could be accessed and how they could apply for them [33, 38, 43, 47, 48, 50].

Older people value healthcare professionals' communication skills

Older people valued interpersonal and educational skills, e.g., regarding explanations of treatment. Healthcare professionals that were "good communicators" helped improve the understanding of care and affected older people positively, e.g., by lessening anxiety [43, 45, 46, 48, 50, 52, 53].

Older people want to be involved in decisions and care

The majority of studies indicated that older persons wanted to be involved in decision-making and planning regarding their healthcare and lifestyle as autonomous and equal partners [35, 37–39, 41, 42, 44–47, 49–51, 53, 54]. This was described as a wish to be asked about needs and priorities, instead of professionals assuming that they knew what these were, and as a wish to be taken seriously [34, 38, 44, 46, 50, 54]. On the other hand, professionals not taking older people's perspective into account, acting in a paternalistic way and not discussing individual concerns or goals were judged negatively [42, 44, 47, 53]. Nevertheless, the minority of the older people wanted to be rather passive, relied on care professionals and wanted them to provide care and make decisions, e.g., regarding hospital admission [35, 37, 41, 44].

Review findings with low appraisal of confidence Older people accept delegation

Regarding general care practices and home visits, most older people accepted task delegation to assistants or nurses, or even welcomed it. On the condition that this person provided a continuous contact, knew them well and exchanged information with a GP or specialist, delegation was found to be a good alternative for minor problems or follow-up appointments, and could even mean that more time and attention was provided for the

older person [34, 37, 47, 50, 51]. Nevertheless, some older people preferred contact with a physician and sometimes considered nurses and assistants to be barriers to physician access [34, 50, 51].

Older people value home visits, but not all think they are necessary

Home visits were discussed controversially in the qualitative studies. In general, it became apparent that receiving a home visit was seen as favorable if someone really needed it but was not required in less urgent cases [34, 51]. Nevertheless, home visits were welcomed as offering the potential for personal attention and as providing more information on the older person's living circumstances and psychosocial context [34, 50, 51]. By contrast, one study on preventive home visits found that these could be too demanding for some ill people [33].

Older people prefer personal information

Older people found it easier to understand information in a face-to-face-conversation, where questions and difficult terms or issues can be discussed directly; brochures or leaflets were requested rather as memory aids [33, 34, 41]. According to the results of two studies, offers of digital services or online communication were refused [47, 50].

Older people want to be informed comprehensively

Older people wished to be informed well about their health status, treatments and further issues by healthcare professionals so that they can understand the procedures [33–35, 38, 41–43, 52]. In contrast, it was reported that some did not wish for more explanations and that they were satisfied with limited information [34, 41].

Discussion

The aim of this study was to summarize the specific preferences and wishes of older people regarding features of ambulatory healthcare. We developed 23 review findings from 22 qualitative studies relating to healthcare structures and care relationships, and appraised the level of confidence in them. Most findings reached a moderate or high confidence level. This was particularly the case for findings that comprised a higher number of contributing studies. Moreover, the inclusion of studies in the systematic review itself was already restrictive regarding characteristics such as the population's age, resulting in a higher relevance for the findings. Additionally, our findings are of a descriptive nature, so the fit between the findings and the respective contributing data was often direct. However, four of our review findings reached only a low confidence level in the evidence. This was mainly due to a lower number of contributing studies and contrary data.

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However, a lower confidence rating does not necessarily mean that the findings were unrepresentative. In these cases, further research is especially needed. This also applies to further care settings from which no or only few studies contributed to the presented review findings. So far, these findings should be transferred carefully to other settings – in particular, when between general healthcare and specific aged-care settings.

Many of our findings with a moderate or high level of confidence are in line with other research, e.g., the wish to stay home for as long as possible [55]. However, other findings are more controversial. For instance, our confidence in the finding that older people accept delegation is low and other research on this matter is also ambivalent. A recent representative survey in Germany showed that the majority of adults accept the shifting of medical tasks to medical practice assistants, but the acceptance varied depending on the specific task (in favor of minor illnesses), and adults aged 65 and over tended to be more unwilling [56]. There are also indications that further variables need to be explored to understand older people's preferences. While our finding that "older people want to be informed comprehensively" received only a low confidence rating due to contrary data, a study on information-seeking preferences among older people (with a mean age of 73 years) found that a lower level of health literacy is associated with a lower desire for information [57]. This is a good example of a feature of care that should be examined in more detail.

A variety of our findings related to aspects of care relationships. This corresponds to other studies exploring the younger age group (65+) or institutional settings. For instance, Bangerter et al. showed that care providers' attitude (interest, friendliness, compassion) and communication (active listening, talking) are very important for nursing home residents aged 80 and over, although in urgent cases, fast professional behaviour was preferred [58]. In a population-based survey on the desirable characteristics of professional long-term caregivers, people aged 65 and over especially valued soft skills such as kindness and empathy, and these aspects were much more important than the provider's gender or ethnical background [59]. In a qualitative study in primary care with people aged 70, Bastiaens et al. also found that good communication skills were valued and that most older patients wanted to have a confidential and caring relationship with their caregivers [60]. Altogether, older people clearly wish to build relationships with care providers and experience empathy.

By contrast, current care models for older people primarily target healthcare structures and the patient's individual behaviour. When compared to our findings, these models do not fit the subjective needs and preferences of

older people. Moreover, it may be possible that this lack of fit affects the success of such models. For instance, some complex care interventions, such as the Geriatric Care Model, did not achieve significant improvements in patients' quality of life or other outcomes [18]. This may be explained by the fact that despite much criticism, Western countries already provide high-level health-care structures [18]. While efforts to reform healthcare structures are nonetheless important and often improve clinical outcomes or decrease the use of services [11], addressing care relationships could also be very promising, as our findings show.

In order to complement care for very old people with effective care relationships, it may be helpful to learn from the concept of relationship-centred care. This attempt to humanize and improve care focuses on patients' relationships and interactions with the care system and their outcomes [61]. Rather than technical communication skills or medical expertise, interpersonal competences are required [62]. Several of our review findings correspond to the elements of relationship-centred care that Dewar and Nolan describe: "willingness to negotiate and compromise, willingness to see another perspective, promoting and accepting the emotions of others, sharing personal information, openness to other ideas, sharing insights when things are not going well, recognizing what people are good at" ([62], p. 1256).

However, the practical reality might look different. One the one hand, primary care providers describe that care for older people is personally and interpersonally challenging [63] and medical students complain about "the emotional burden of caring for older patients" ([64], p. 1996). On the other hand, focusing on relationships rather than on the medical aspects of care may not meet professionals' expectations and ambitions, and therefore may make caring for older people unattractive [64]. Since older patients are expected to be seen more frequently in most medical subspecialities, apart from geriatrics, addressing attitudes and interpersonal competences in all healthcare professions seems necessary. In the systematic review of Tullo et al. on teaching interventions to improve the knowledge, skills and attitudes of medical students, increased exposure to older patients and longterm teaching implementation were found to be effective [65]. Furthermore, geriatric issues should be presented as "intellectually challenging and emotionally appealing" ([66], p. 241). However, multicomponent interventions in primary care still mainly focus on care structures such as access. Only a few include provider education and training and among these, the content of the training often refers to disease-specific knowledge [67]. Therefore, primary care interventions and innovations do not comprehensively prepare for the growing number of older adults Herrler et al. BMC Geriatrics (2022) 22:428 Page 19 of 21

in the population, and seldom address providers' attitude and care relationships.

Altogether, it becomes clear that besides ambulatory healthcare structures, several features of care relationships are important to people aged 80 and over. While our findings provide an overview of the relevant features of care, future research should further explore these and their impact on relevant patient and care outcomes to enable age-appropriate care. The features of care presented in this paper may serve as a basis for investigations in other (especially non-European) countries and cultures. Moreover, they could provide a basis for quantitative investigations such as discrete choice experiments to strengthen the inclusion of the perspective of people aged 80 and over in the design of healthcare. However, this should not replace discussions about older people's wishes and preferences in individual care situations.

Strengths and Limitations

To our knowledge, this is the first systematic overview of the preferable features of ambulatory care from the perspective of people aged 80 and over. The work benefits from a base of 22 studies, which were systematically searched and appraised. Moreover, the rigorous application of CERQual allows for detailed insight into the confidence that can be put in the findings; this therefore strengthens their potential for incorporation into evidence-based decision-making. Since CERQual is a tool designed for qualitative research synthesis, it particularly serves the requirements of qualitative research, instead of referring to frequencies to provide an appraisal of confidence in the evidence. Additionally, the presented approach of analysis and confidence appraisal is particularly suitable to promote the systematic incorporation of qualitative evidence for practice-oriented problems and policy questions (e.g., as in comprehensive health technology assessment reports). Therefore, it complements integrating or theorizing approaches such as meta-ethnography in providing a deeper understanding of, e.g., patients' perspectives.

However, some limitations should be considered. Firstly, the selection of studies is based on an earlier systematic review and all of its limitations apply here as well: 1) the risk of unconsidered data due to dissemination bias and the restriction to English, German and Dutch publications; 2) restricted transferability to other countries because most of the included studies were conducted in Northern and Western Europe; and 3) restricted transferability to certain care settings, such as dental care, since the studies included did not cover them [23]. Secondly, CERQual is a relatively new tool for appraising qualitative review findings, especially regarding care for older people and their preferences. There may have been pitfalls in

the application that we have not registered. In particular, the use of another tool for the appraisal of methodological limitations might have resulted in slightly different confidence ratings.

Conclusions

This meta-summary provides a set of 23 preferable features of ambulatory care from the perspective of people aged 80 and over. The findings highlight the role of care relationships, which seem to be as yet underrepresented in the design of healthcare. Further research should explore the single features in more detail and their possible effects on patient outcomes and quality of care. The use of qualitative research syntheses in combination with CERQual, as described in this paper, has the potential to allow for systematic inclusion of patients' perspectives in the design and development of care.

Abbreviation

CERQual: Confidence in the Evidence from Reviews of Qualitative Research.

Supplementary Information

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Additional file 1. Assessment of methodological limitations.

Additional file 2. Assessment of coherence and adequacy.

Additional file 3. Assessment of relevance.

Additional file 4. CERQual evidence profile.

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Authors' contributions

AH: Conceptualization, Methodology, Formal Analysis, Investigation, Writing – Original Draft, Writing – Review and Editing, Visualization, Project Administration. HK: Formal Analysis, Investigation, Writing – Review and Editing. VV: Conceptualization, Methodology, Writing – Review and Editing. SS: Conceptualization, Methodology, Writing – Review and Editing, Supervision. All authors have read and approved the manuscript.

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Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Not applicable.

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Consent for publication

Not applicable.

Competing interests

The authors declare that there are no conflicts of interest.

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Appendix: Publication 3

Publication 3

Characteristics of desirable ambulatory health and oral healthcare from the perspective of community-dwelling people aged 80 and over — A qualitative examination

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Characteristics of desirable ambulatory health and oral healthcare from the perspective of community-dwelling people aged 80 and over – A qualitative examination

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Abstract

Background. People aged 80 and over frequently have diverse and complex health trajectories, which has been well studied. But their oral health is seldom included in care models. To realise comprehensive healthcare, both general and oral ambulatory (i.e., outpatient) healthcare need to be explored and conceptualised equally.

Objective. To elicit what matters to very old people regarding ambulatory health and oral healthcare.

Methods. Interviews were conducted with non-institutionalised people aged 80 and over living in the area of Cologne, Germany. They were interviewed regarding their experiences of and views on ambulatory healthcare and oral healthcare care, respectively. Thematic analysis was performed to understand their motives and elicit relevant characteristics of desirable health services.

Results. From the interviews with 22 participants, 16 characteristics of good healthcare were described. These were generally similar for both general and oral healthcare and had a particular focus on patient-provider-interaction and the organization of care. However, regarding oral healthcare, the participants focused more strongly on the technical-medical skills of professionals and the perceptible treatment results and were more concerned about costs. It was noticeable that older people had the urge to differentiate themselves from "others unnecessarily using health services". They were unaware of possible future oral health deterioration and the resulting future needs.

Conclusions. Characteristics of good health and oral healthcare from the perspective of older people should be incorporated to ensure patient-centredness in care models. Older patients, as well as healthcare providers, need to be sensitised to their oral health needs to realise comprehensive healthcare.

Keywords

Aged, 80 and over; ambulatory healthcare; oral health; gerodontology; qualitative research; older people

Key Points

- The area of oral healthcare for older people had been underexamined and was rarely considered in comprehensive healthcare.
- Based on qualitative data, 16 characteristics of desirable ambulatory health and oral healthcare were elicited.
- A lack of awareness of oral health deterioration was noticeable, compared to high awareness of general health deterioration.
- Oral health matters should be included more fully in a comprehensive concept of caring for older adults.
- Joint training opportunities for general and oral healthcare providers could be a promising approach.

Introduction

The global population of people aged 80 and over is growing steadily. In Europe, the proportion of the population of such almost doubled to six percent between 2001 and 2020 [1]. Although ageing is not a linear process of deterioration [2], several health issues are more prevalent in this age group, especially multimorbidity (the occurrence of two or more chronic conditions simultaneously) and frailty [3, 4]. While these age-related conditions are well-known and have been broadly studied [2], older people's oral health is seldom included in the debate about their healthcare [5, 6]. But dental treatment needs, comprising caries, periodontal disease, non-functional prostheses and chewing problems, are common [7-13]. In particular, frail older adults and those with complex care needs have a higher prevalence of problems, such as oral pain and dry mouth, that, in complex interactions between frailty, immunosenescence, oral microbiome and oral hygiene and health, affect their lives [14, 15]. Although oral health plays an important role in health-related quality of life [16], it is still mainly considered separate from overall health in research and practice. Care models for older people claiming comprehensiveness seldom include oral healthcare or dentists as part of interdisciplinary care planning, as can, for instance, be seen in the overview of Boult et al. [17]. This is striking because, in contrast to the rest of ambulatory (i.e., outpatient) healthcare, the frequency of dental care contacts decreases with age, possibly resulting in underuse and unmet oral health needs [7].

However, in the past years, the field of gerodontology and oral health services research has caught up. Studies have shown that older people as well as other healthcare professionals and caregivers 1) are less aware of or lacking knowledge regarding oral health needs, 2) hold views on oral healthcare that are influenced by the relevance that was put on oral health in their previous life, and 3) lack of transport possibilities and additional costs are important barriers to using oral healthcare [18-24]. While the available studies provide important insight into the role of oral health and care for older people, they were still performed separately.

Hence, this study aimed at exploring the views of older people regarding what constitutes good healthcare, incorporating general and oral healthcare equally, to provide a basis for holistic care models. We focused on community-dwelling people aged 80 and over not being dependent on care since the goal of proactive healthcare is to avoid institutionalisation and care dependency, as far as possible [25, 26], and other studies have often focused on the "younger old" (65+ years) [2]. The overall research question was: What matters to older people regarding ambulatory health and oral healthcare?

The study was conducted in Germany, where the healthcare system is divided into three sectors: ambulatory (outpatient) healthcare, hospital (inpatient) healthcare and rehabilitation. In the ambulatory healthcare sector, general practitioners, specialists and dentists provide health and oral health services in their own or in cooperative local offices that that can be freely chosen by patients [27]. Hence, they are similarly organised. Most of the services are covered by the statutory health insurance system, which includes almost 90% of the population. However, private co-payments for more or higher quality services are possible, especially in dentistry (e.g., to receive a ceramic instead of amalgam filling for aesthetic purposes) [27].

Methods

We positioned our study design in an experientialist/realist paradigm. Therefore, we conducted qualitative interviews using a semi-structured interview guide to talk with the participants on certain guiding topics, but to be still open and flexible enough to let them raise and explain what was important to them [28]. The study was approved by the Medical Ethics Review Board of the Medical Faculty at the University of Cologne (19-1645) and registered in the German Clinical Trials Register (DRKS00020889). Reporting of the study is based on the consolidated criteria for reporting qualitative studies (COREQ) [29]. Figure 1 provides an overview of the methodological process.

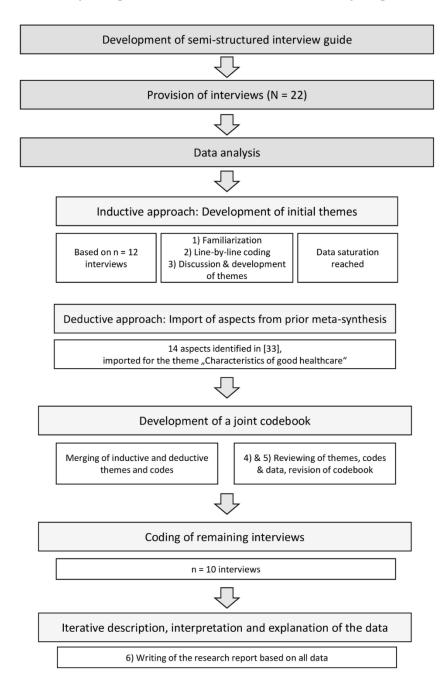


Figure 1: Overview of methodological process

Development of the interview guide

The interview guide was developed by a health services researcher (AH) and a speech therapist (HK), both conducting research in the field of gerontology, and a health economist (VV) and a physician (SS), both conducting research in the field of patient-centred care. Additionally, a dentist (AGB) trained in gerodontology was involved. The guide's structure followed a stepwise approach: After an introductory part (small talk and asking about the person's overall well-being), participants were asked to 1) describe one or more previous ambulatory healthcare or dental care situations, 2) explain whether they had experienced "good" healthcare, from their perspective, and 3) elaborate on the reasons for this assessment and the subjective relevance of certain aspects. Additionally, we developed a short questionnaire on sociodemographic and health characteristics to be able to describe the sample in more detail. The interview guide was refined during a discussion among the research team and subsequently pretested with one woman (81 years) and one man (86 years). After the pretest, only minor changes regarding the wording and arrangement of the questions were implemented, so the pretest interviews were included in the analysis. An overview of the interview guide appears in Table 1. All participants were interviewed using the same guide, apart from one difference: Half of the sample was asked to refer to general ambulatory healthcare, and the other half was asked to refer to oral health/dental care. This was done to ensure that both ambulatory healthcare areas would be explored equally and deeply enough, since the previous research showed that older people might prioritize dental care less and may predominantly refer to general healthcare if both were approached in one interview.

Table 1: Summary of interview guide

Key topic	In-depth topics
General well-being	 Support needs in daily life Occasions for seeking healthcare
Positive outpatient healthcare/outpatient dental care experiences	 Sequence Reasons for positive evaluation Relationship with core motives (feeling safe, feeling like a meaningful human being, maintaining control and independence)
Negative outpatient healthcare/outpatient dental care experiences	 Sequence Reasons for positive evaluation Relationship with core motives (feeling safe, feeling like a meaningful human being, maintaining control and independence)
Subjective significance of outpatient healthcare/outpatient dental care	 Reasons Role regarding general well-being Relationships with healthcare providers
Ideas of ideal outpatient healthcare/outpatient dental care	ReasonsPriorities
The potential impact of the Covid-19 pandemic on views regarding outpatient healthcare/outpatient dental care	

Sampling, recruitment and data collection

A purposive sampling strategy [30] was applied to reach diversity regarding sociodemographic and health aspects (especially sex, educational status, and subjective health status). People were eligible for participation if they were at least 80 years old, were community-dwelling (living in a non-institutionalised setting) in Cologne, and could participate in the interview in German. Participants were recruited via advertisements in two local newspapers, notices in the local university hospitals and cooperating medical practices, and information spread through community institutions such as seniors' sports clubs or volunteering institutions. If a person was interested in participating, they first made a phone call to (AH) to gain further information on the study, to check whether they were eligible and to appoint a date for the face-to-face interview. Before the start of the interview, written informed consent was obtained.

After the interview, participants received an allowance of 15 euros as appreciation for their participation. The interviews were audio-recorded and transcribed verbatim to facilitate in-depth data analysis [28]. All the interviews were conducted by (AH).

Data analysis

We used thematic analysis to enable both descriptions of what good healthcare constitutes and an understanding of the participant's motivations and actions [31]. Overall, our analytic approach was twofold: First, we wanted to inductively explore and interpret the data by developing themes ("[capturing] something important to the research question, and [representing] some level of patterned response or meaning within the data set" [31, p. 82]). Therefore, (AH) and (HK) independently 1) familiarised themselves with data, obtained from 12 interviews and 2) inductively coded the data line by line. All coding was facilitated using MAXQDA Analytics Pro 2020 (VERBI Software, Berlin). After checking the initial codes for redundancies, the codes were 3) organised into broader themes discussing among the whole research team, what was found to matter to the participants when talking about their perceptions of healthcare [31]. The initial independent coding was not done to calculate intercoder reliability later but to make the analysis broader in the beginning, with each researcher building a separate first understanding of the data. Additionally, this approach allowed the researchers to discuss whether they found that data saturation ("the degree to which new data repeat what was expressed in previous data" [32, p. 1897]) was reached. Since this was the case, it was decided to stop further data collection.

One of the initial themes (from step 3) comprised descriptions of what constituted good healthcare. To tie in with the research status, we then decided to adopt a partially deductive approach for this specific theme. A recent meta-synthesis had already integratively explored the underlying motives of people aged 80 and over regarding ambulatory healthcare, based on 22 qualitative studies [33]. The study provided an initial framework of 14 aspects relevant to good healthcare, although no studies covering older people's views on oral healthcare could be included and the contributing studies mostly originated from specific aged-care settings such as home care [33]. We decided to incorporate the already identified 14 aspects as a basis to explore the theme of "good healthcare", while also aiming to further develop it with our data.

To facilitate the analysis incorporating both inductive and deductive elements, we meanwhile developed a codebook to structure the data. As Braun and Clarke describe, "the codebook is used to record and or chart the developing analysis as well as to guide data coding" [34, p. 5]. Both codes and themes already found inductively and the deductively imported 14 aspects were brought together. Following steps 4) and 5) of Braun and Clarke's thematic analysis, we now reviewed the entirety of our themes interacting with our codes and data [31] in a discussion among all authors, which also included a revision of the

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codebook. Based on the final codebook, (AH) coded the remaining ten already conducted interviews in consultation with (HK) to ensure all the data could be used to substantiate the research results. All the data was finally reread and used for iterative description, interpretation and explanation in 6) writing up the research report, which was led by (AH) in close collaboration with (HK), and the interim and final results were further discussed by the entire research team.

Results

From October 2020 to July 2021, 22 people participated in the study. The median age was 82 years (range: 80-88 years) and two-thirds of the participants were female. More detailed information is provided in Table 2. Apart from three interviews that took place at the university, all the interviews were conducted at the participants' homes.

In the following, the core themes, including interview examples will be presented. AH translated the interview examples from German to English to enable better comprehension, and the translations were checked by an external English native speaker. An overview of all interview examples with their original German version is provided in Table 3. Additionally, an overview of all themes is provided in Appendix A.

Table 2: Sample characteristics

Variable

Age: mean/median	(range)	83/82 (80-88)
Median household	size (range)	1 (1-2)
Sex	Female	14
	Male	8
Marital status	Married	7
	Widowed	11
	Unmarried	1
	Divorced	3
Last graduation	None	0
	Secondary school	8
	Middle school	7
	Higher education entrance qualification	6
Professional	None	0
qualification	Apprenticeship	11
	Vocational school	4
	University of applied sciences/university	6
	Other	1
Health insurance	Statutory	19
	Private	3
Supplementary	None	16
insurance	Only for dental care	4
	Other	1
	Both for dental care and other	1
Current subjective	Good	8
health status	Rather good	9
	Rather bad	4
	Bad	1
Current subjective	Good	17
oral health status	Rather good	1
	Rather bad	3
	Bad	1
Median number of	chronic health issues (range)	2,5 (0-5)
Median number of	oral health issues (range)	0 (0-3)
Median number of	prescribed medications (range)	3 (0-10)
Median number of	general practitioner or specialist visits in the past six months (range)	3 (0-9)
Median number of	dentist visits in the past twelve months (range)	1 (0-8)
Median number of	hospital visits in the past twelve months (range)	0 (1-2)
Duration of intervie	ws: mean/median (range)	42/41 (22-92)

Citation: Herrler A, Kukla H, Barbe AG, Vennedey V, Stock S. Characteristics of desirable ambulatory health and oral healthcare from the perspective of community-dwelling people aged 80 and over – A qualitative examination. Age Ageing. 2022;51(11): afac258. doi: 10.1093/ageing/afac258. By permission of Oxford University Press/British Geriatrics Society.

Table 3: Original and translated illustrative interview passages

Theme	Illustrative interview passage (English translation)	Illustrative interview passage (German original)
Older people's views of themselves and their hea status	"I can't do foot care anymore. My son does that. And I know that I am entitled to get home care if I need that" (A8, §60)	"Ich kann ja auch nicht mehr Fußpflege machen. Das macht mein Sohn. Und ich weiß, es stehen mir dann ja auch Pflegekräfte zu, wenn ich sie mal brauche" (A8, §60)
	"As for the teeth, I don't know, if at some point you are no longer able to stand in front of the mirror for so long. Well, then you could still sit down. With the mirror. Then the bathroom would have to be rebuilt so that you have the mirror in front of you while sitting, for example. You still have to do that yourself, and I don't know how that's going to work." (B3, §59-60)	"Was die Zähne angeht, das weiß ich nicht, wenn man irgendwann nicht mehr in der Lage ist, solange vor dem Spiegel zu stehen. Gut, dann könnte man sich noch setzen. Mit dem Spiegel. Dann müsste das Badezimmer so umgebaut werden, dass man den Spiegel so vor sich hat im Sitzen. Zum Beispiel. Das muss man ja selber machen nach wie vor, wie das dann gehen soll, das weiß ich nicht." (B3, §59-60)
Older people's general perceptions of ambulator health and oral healthcar		"Aber das ist so, als könnte der mit älteren Leuten nichts anfangen" (A5, § 26)
Older people's views on the utilization of health services	"They try to be friendly, but you recognize, what is always in the background, 'Oh my gosh, what shall we further do?' I know that there is also a truth in that" (B9, § 19-20)	"Man bemüht sich um die Freundlichkeit, aber Sie merken, dass da hinter immer steht, oh Gott, was wollen wir bei der denn noch machen? Ich weiß, dass da ja auch Wahrheit drin liegt" (B9, § 20)
	"First of all, it was important to me to know that we are able to afford [the routine examination]" (A11, §34)	"Also für mich war das erstmal wichtig zu wissen, dass wir uns eine solche Sache [den Check-Up] leisten können" (A11, §34)
Charac- teristics of health and oral ambulatory health and providers	of "I can tell by the way the doctor acts and talks whether he has a clue or not. And he also thinks the issues through with me." (A4, §16)"	"Am Gehabe und am Sprechen des Arztes merke ich das schon, ob er Ahnung hat oder nicht. Und er überlegt ja auch mit und so weiter." (A4, §16)
oral healthcare	"And I always have the feeling that I think, he can't keep studying at university. In my opinion, he is always up to date" (B9, §8)	"Und ich habe immer das Gefühl, dass ich denke, der kann doch nicht immer weiter der Uni studieren" (B9, §8)
Patient- provider- interaction	"Now I have the feeling, there are too many people. There are several older people who are bored and don't feel well and they go to the doctor for every little thing" (A1, §42)	"Jetzt habe ich das Gefühl, da sind zu viele Menschen, es gibt auch viele ältere Leute, die haben Langeweile und die fühlen sich nicht gut und gehen bei jedem Pups zum Doktor" (A1, §42)

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Theme		Illustrative interview passage (English translation)	Illustrative interview passage (German original)
		"They don't want that. You cannot say that. One thinks, one knows more than the doctor, so you have to be careful" (A6, §30)	"Das wollen die nicht. Das dürfen Sie nicht sagen. Man denkt, man weiß mehr als der Arzt, da muss man also vorsichtig sein" (A6, §30)
		"It is awful, although to a certain extent understandable. They look at their computer, they are talking to you, but they look at their computer. Constantly" (A8, §18)	"Was bei allen so scheußlich ist, bis zu einem gewissen Grad auch verständlich, da gucken die auf den Computer, aber die reden mit dir, gucken aber auf den Computer. Konstant" (A8, §18)
	The output of health and oral healthcare	"Which doctor will take care of you, I thought, and really listen to you and inquires. And not, 'that will probably be it' and prescribe something" (A1, §61)	"Welcher Arzt kümmert sich um dich, habe ich gedacht, und hört mal richtig zu und forscht mal nach. Und nicht, das wird das wohl sein und verschreiben" (A1, §61)
		"And I live happily with that, the dental crown lasts, I have teeth there and can laugh and nobody sees that I lost my teeth" (B7, §22)	"Und mit dem lebe ich glücklich die Krone hält und ich habe da hinten Zähne und ich kann lachen und keiner sieht, dass mir ein paar Zähne fehlen" (B7, §22)
		"When I listen to my wife, she says, you are a private patient, everything is different, they talk to you differently. With me, they take the time for me. Because I pay for that" (A11, §44)	"Wenn ich immer von meiner Frau höre, du bist ja Privatpatient, das ist bei dir ja alles anders und die reden mit dir auch anders. Bei mir nehmen sie sich Zeit. Ich bezahle das ja" (A11, §44)
		"The dentist said to me, I have such a minimal jaw left here, I have to have implants. Two implants. Two or four. Two in the back are there to be fixed. But the cost of that. That's the problem" (B6, §10)	"Der Zahnarzt hat zu mir gesagt, ich hätte hier unten den Unterkiefer so minimal, ich müsste Implantate haben. Zwei Implantate. Zwei oder vier. Hinten zwei und da, dass das festgemacht wird. Aber was das kostet. Das ist das Problem" (B6, §10)
	Organisation and context of health and oral healthcare	"When I say I'm in pain. It's exactly the same. When I'm on the phone, 'yes, in three weeks or so'. Then I say no, I have such pain. I've waited so long now, I can't go on. I want to see the doctor now. 'Yes, if you have waited so long, then you can wait another three weeks'. That's not possible" (A10, §58)	"Wenn ich sage, ich habe Schmerzen. Das ist genau das Gleiche. Wenn ich am Telefon bin, ja in drei Wochen oder so. Dann sage ich nein, ich habe solche Schmerzen. Ich habe jetzt so lange gewartet, ich kann jetzt nicht mehr. Ich möchte jetzt zum Herrn oder Frau Doktor. Ja wenn Sie doch solange gewartet haben, dann können Sie ja auch noch drei Wochen warten. Sowas geht gar nicht" (A10, §58)

1) Older people's views of themselves and their health status

Reports on age-related restrictions and thoughts about the deterioration of health were common in all interviews. Most frequently, the participants reported restrictions in mobility and the reduction or replacement of certain activities. It became apparent that they had adapted their lives and meaningful activities to their current condition, while also attaching importance to maintaining their usual lifestyle. Hence, they emphasized the role of prevention and wished for thorough examinations and support should help be needed. Although they wanted to delay dependence on help as long as possible, to receive support at some point was expected and accepted: "I can't do foot care anymore. My son does that. And I know that I am entitled to get home care if I need that" (A8, §60).

While it became apparent that the older people wished to be seen holistically in healthcare, they rarely included their oral health in their reflections. Only three participants made oral health issues a subject of discussion. In these cases, hampered oral hygiene due to an inflammation in the arm, loss of teeth and swallowing problems were addressed. One interviewee, an 82-year-old man, discussed the future of his oral health and hygiene and reflected on measures that may help him brush his teeth: "As for the teeth, I don't know, if at some point you are no longer able to stand in front of the mirror for so long. [...] You still have to do that yourself, and I don't know how that's going to work" (B3, §59-60). It was notable that these considerations only comprised measures that might enable self-provision of oral hygiene. Thus, while it seemed normal for older people to consider receiving external help for physical issues such as foot care, this did not apply to oral hygiene.

2) Older people's general perceptions of ambulatory health and oral healthcare

The participants reported general satisfaction with their healthcare. However, several negative experiences from interactions with healthcare providers were described, sometimes connected to the perception of being treated worse due to their older age: "It is as if he disliked older people" (A5, §26). Interestingly, the participants seemed to be more confident about changing providers in dental care, in contrast to GPs and specialist physicians. This might be due to a wider offer of available dental care practices or may be associated with the usually higher private co-payments.

3) Older people's views on the utilization of health services

Most participants reported that they avoided "unnecessarily using health services". Whether health services use was perceived as appropriate seemed to be driven by a generally negative perception of older people as "unnecessary healthcare users" or "blocking" healthcare resources: "They try to be friendly, but you recognize what is always in the background, 'Oh my gosh, what shall we further do?' I know that there is also a truth in that" (B9, § 20). The participants described that in their perception, they used health services only if necessary, e.g., for acute occasions. Regarding dental care, avoidance was also explained by appointments being perceived as cumbersome and unpleasant. Interestingly, a good result of dental care – e.g., no need to repair a tooth or a well-fitting denture – seemed to support the perception of visiting the dentist as unnecessary. Concerns about out-of-pocket costs also played a role, particularly among privately insured persons and regarding dental care: "First of all, it was important to me to know that we are able to afford [the routine examination]" (A11, §34).

4) Characteristics of good ambulatory health and oral healthcare

Based on the prior meta-synthesis, three new aspects of desirable health and oral healthcare were identified: the result of healthcare, costs, and practice characteristics. One prior aspect (activation) was not represented in our study. In total, 16 characteristics were elicited in four areas: 1) attributes of health and oral healthcare providers, 2) patient-provider-interaction, 3) the output of health and oral healthcare, and 4) organisation and context of health and oral healthcare. An overview of all characteristics is presented in Figure 2.

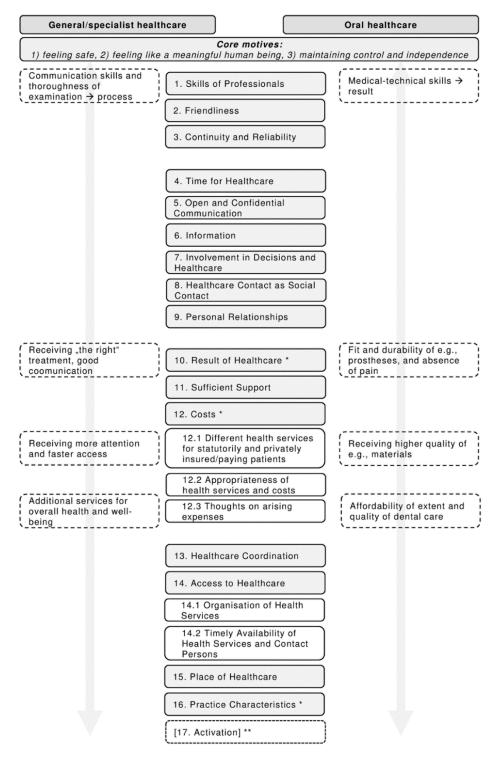


Figure 2: Results concerning characteristics of desirable ambulatory healthcare and oral healthcare

Notes: Numbers 1-15 represent the characteristics of desirable ambulatory health and oral healthcare, based on relevant aspects found in a previous meta-synthesis interacting with three core motives [33]. Characteristics are grouped as attributes of health and oral healthcare providers (1-3); patient-provider-interaction (4-9); the output of health and oral healthcare (10-12); organisation and context of health and oral healthcare (13-16). *Aspect was not included in the prior meta-synthesis. **Aspect was included in the prior meta-synthesis, but not relevant in this study. Explanations in the dotted boxes indicate substantially different interpretations of the respective characteristics.

4.1) Attributes of health and oral healthcare providers

Friendliness was considered a basic characteristic of good healthcare. By friendliness, participants meant being treated empathetically and respectfully and having their concerns taken seriously. This was often supported in small, casual conversations. The participants also expressed the wish to interact with the same healthcare providers, if possible. The continuity of healthcare providers gave them a feeling of familiarity and safety. For good healthcare, the perception of healthcare professionals' skills and competencies was also considered important. This was based on personal relationships, trust and the ability to explain and communicate satisfactorily: "I can tell by the way the doctor acts and talks whether he has a clue or not. And he also thinks the issues through with me" (A4, §16). Regarding dental care, the healthcare providers' competence was more strongly described referring to their work as "state of the art", with a perception of continuous training and respective counselling regarding treatment methods and use of materials: "And I always have the feeling that I think, he can't keep studying at university. In my opinion, he is always up to date" (B9, §8). The perceived result, e.g., the durability of dentures, was especially important in describing a dentist as competent.

4.2) Patient-provider-interaction

Having *sufficient time* in patient-provider interactions was an important feature of good healthcare. Participants wished to be granted enough time to explain their concerns, to receive information and a thorough examination, and be offered an atmosphere that was not rushed. However, several participants narrated negative experiences, in that they felt frequently hurried and were not taken seriously. Comprehension of and explanations for this problem were discussed, and they included general economic and time pressure in the healthcare system, and the perception that "other older people" would unnecessarily use healthcare and waste the providers' time: "Now I have the feeling, there are too many people. There are several older people who are bored and don't feel well and they go to the doctor for every little thing" (A1, §42).

Open and confidential communication was considered necessary for well-being and the best possible healthcare results. It was the basis for trust and allowed the older people to raise all their concerns, providing a complete picture of their health status and treatment options. They wanted to be listened to without restrictions and that an atmosphere was created in which they could raise sensitive concerns. The participants also wished to receive comprehensive *information*, such as explanations of indications, treatment and medication, and an opportunity to discuss possible treatment options. Although four participants stated that they mostly did not want to discuss such matters because they trusted the provider to do the best for them or did not perceive that more than one option might be available, the majority clearly expressed the wish to be involved in decisions and healthcare as equal partners. Receiving too little information resulted in uncertainty, doubts and the perception that providers were not interested in them. On this matter, there were several reports of inhibited communication, especially regarding questions "the doctor might not like". And some older people had the feeling that their engagement in therapy discussions and their opinions were undesired: "They don't want that. You cannot say that. One thinks, one knows more than the doctor, so you have to be careful" (A6, §30).

The older people also negatively reported on healthcare interactions focused only on acute issues, leaving out long-term planning and quality of life; instead, they wanted to receive holistic advice beyond an acute occasion, e.g., regarding lifestyle and prevention measures.

Overall, the participants wanted to be primarily perceived as humans engaging in regular *social contact*, which could, for instance, be achieved through casual conversation. As one woman said, healthcare contacts were often strongly focused on "the current case" and the interactions did not feel pleasant: "It is awful, although, to a certain extent, understandable. They look at their computer, they are talking to you, but they look at their computer. Constantly" (A8, §18). This shows that the interpersonal interaction affected the participants' feelings of trust, safety, and well-being. These perceptions were also reflected in their wish to build long-term *personal relationships* with healthcare providers, comprising a more than superficial knowledge about the other person that was not limited to medical indications.

4.3) The output of health and oral healthcare

The *result* was an important characteristic of good healthcare for all the participants. Regarding general practice and specialist healthcare, a good result mainly referred to the perception of receiving the *right* treatment, which could be achieved through good information and communication: "Which doctor will take care of you, I thought, and really listen to you and inquires. And not, 'that will probably be it' and prescribe something" (A1, §61). The absence of pain and the preservation and restoration of functions such as the ability to walk were also mentioned. Regarding dental care, the perception of a good result especially comprised good fit of prostheses and dentures, durability, and the absence of pain. The feeling of clean teeth after treatment, the long-term preservation of teeth, easy manageability of dentures and aesthetic appearance were also relevant criteria: "And I live happily with that, the dental crown lasts, I have teeth there and can laugh and nobody sees that I lost my teeth" (B7, §22). The different perceptions might be explained by the fact that the result of dental care is more visible than, e.g., a person's blood pressure.

Sufficient individual support was another important characteristic of good healthcare. This referred to individual counselling, thorough examinations and treatment, including follow-up appointments, listening well, and taking concerns seriously. Moreover, the participants wished to be directed to additional support services and wanted physicians to explain medication prescriptions.

The costs played an important role in older people's perceptions of receiving good and appropriate healthcare. Several participants spoke about their perception that privately insured patients and direct payers receive more comprehensive and better health services, that they receive more attention from physicians and that they have faster access. A privately insured participant reported: "When I listen to my wife, she says, you are a private patient, everything is different, they talk to you differently. With me, they take the time for me. Because I pay for that" (A11, §44). This was considered a societal problem of injustice. Regarding oral healthcare, there was the perception that direct payers received better quality care, e.g., regarding the material of dentures. But, some thought that privately insured patients may also receive unnecessary health services. On this matter, the appropriateness of costs and health services was discussed as a criterion for receiving good healthcare. The participants argued that distinguishing between a necessary service, e.g., a certain material used in dental care or a directly paid additional blood examination, and a nice-to-have-service that was offered to increase the payment was not always easy. The older people described generally thinking about the costs of health and dental care. Regarding oral healthcare, these thoughts were primarily about whether and to what extent quality care could be afforded. One concern was that co-payments could not be afforded; as a result, some participants had already avoided or postponed dental care. "The dentist said to me, I have such a minimal jaw left here, I have to have implants. Two implants. Two or four. Two in the back are there to be fixed. But the cost of that. That's the problem" (B6, §10). It was also mentioned that the statutorily paid services may be Citation: Herrler A, Kukla H, Barbe AG, Vennedey V, Stock S. Characteristics of desirable ambulatory health and oral

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sufficient but did not provide the aesthetic appearance needed to feel well. Conversely, the concerns about costs regarding GP or specialist care referred more to additional services, especially in counselling, prevention and rehabilitation.

4.4) Organisation and context of health and oral healthcare

Healthcare coordination was only discussed regarding general healthcare, probably because of more frequent referral processes. Healthcare coordination refers to healthcare processes working seamlessly, especially regarding referral appointments and the exchange of information between different healthcare providers. But two participants felt unhappy about that, e.g., due to a general mistrust in the healthcare system.

Access to healthcare comprised two dimensions. First, the organisation of health services was discussed. Participants wished that healthcare processes, appointment allocations and regular visits were organised properly so that no uncertainties regarding their treatment or waiting times would occur. Second, timely availability of healthcare and contact persons was an important aspect, but there were mixed opinions about the availability of services. Several participants stated that in the case of urgent need, medical help was readily available. However, they complained about long waiting times, especially regarding specialist appointments. In their perception, they had already tried to avoid healthcare use as far as possible, so when they decided to consult a physician, it was with a high perception of urgency: "When I say I'm in pain. It's exactly the same. When I'm on the phone, 'yes, in three weeks or so'. Then I say no, I have such pain. I've waited so long now, I can't go on. I want to see the doctor now. 'Yes, if you have waited so long, then you can wait another three weeks'. That's not possible" (A10, §58). Regarding oral healthcare, the reported experiences were more positive. Most participants were satisfied, although they suggested providing more short-term appointments or open practice hours to support flexibility.

Since all the participants were still living in their own homes, the *place of healthcare* did not play a major role in the interviews. But, in the case of increased support needs, they wished to continue living at home, if possible. Regarding *practice characteristics*, the older people held mixed opinions. On the one hand, a modern, well-equipped practice was appraised positively and had a good atmosphere and gave them the feeling of being well cared for. On the other hand, a practice that seemed to be too modern or luxurious was appraised negatively because of the impression that appearance and money were focused on.

Discussion

This qualitative study investigated what matters to community-dwelling people aged 80 and over regarding both ambulatory health and oral healthcare. We described 16 characteristics that constitute a framework of good healthcare and how these are shaped: through their views on their own health, their general perception of healthcare and their views on the utilization of health services. The framework provides the basis for a patient-centred understanding and development of care for older people, particularly including oral healthcare. As the results show, what is good healthcare was mostly considered to be the same for both general and oral healthcare, especially regarding patient-provider-interaction and the organization of care. The differences mainly regarded what was a perceptible treatment result, with perceptions of oral healthcare having a stronger technical-medical focus. They were also related to perceptions of the provider's competence and which benefits, on paying the health service directly, could be offered. This could be substantiated by the fact that co-payments are more usual for oral healthcare in Germany [27]. Since most aspects were similar, it should be possible to conceptualise comprehensive healthcare and care models for older people including oral healthcare.

Our findings on the characteristics of desirable health and oral healthcare are similar to elements in the conceptualisations of patient satisfaction (e. g, [35, 36]) and patient-centredness [37, 38]. Interestingly, while the participants said how they were generally satisfied, they reported several negative experiences. Consequently, this study might indicate that health and oral healthcare do not necessarily have to meet all the specific wishes or expectations of (older) patients to achieve satisfaction or patient-centredness. As the prior meta-synthesis noted, basic requirements must be fulfilled, and these seem to be *feeling safe*, *feeling like a meaningful human being* and *maintaining control and independence* [33]. They can be addressed within nearly all of the identified characteristics and should, therefore, form the basis for the provision of health and oral healthcare for older patients (Figure 2). "Costs" and the "result of healthcare" were new aspects compared to prior studies [37-39] and were rather introduced concerning oral healthcare. Hence, these factors should be further explored among very old patients to understand their implications for the use of dental care and satisfaction, especially against the background of underuse [7].

Apart from that, two findings were striking. First, nearly all the participants were concerned about general health deteriorations and age-related restrictions and talked about the importance of considering a holistic view of health but were rarely aware of possible expected oral health deterioration, future oral care or increased oral hygiene needs. This is in line with other studies, e.g., a cross-sectional examination in France that found that older people were seldom aware of their preventive and curative oral care needs [9]. Since there are considerable treatment needs in old age, older people should be informed more comprehensively about oral health and dental care. Providers of ambulatory healthcare could be a key factor in paying attention to oral health aspects when in contact with older patients, e.g., by informing them about oral health and using oral health screening tools, followed by a presentation to a dentist [40-42]. An important part of providing comprehensive proactive care could be the reduction of discomfort with the help of oral hygiene by actively addressing and normalizing it during, for instance, routine examinations. But since prior research has shown that healthcare providers who are not trained for oral healthcare are often lacking awareness of oral health as well, broader inclusion of the topic in their education and training is probably needed [5, 20]. But, oral healthcare providers should also be made aware of older people's overall healthcare situations and needs [5], and they should address the importance of long-term oral healthcare development early, even though the patient might have no current unmet needs.

A second noteworthy finding concerns the participants' perceived images of older people in healthcare. They often talked about others "unnecessarily blocking" healthcare resources or "wasting valuable time" and seemed to have a great urge to differentiate from "those" older people. From our results, the perception of healthcare professionals not being genuinely interested in older people as persons might strengthen this perception. Addressing attitudes and beliefs toward older people in the training of healthcare professionals might be a promising approach [43]. Joint education and interdisciplinary training opportunities between GPs, specialists and dentists, developed and conducted involving all disciplines, could further enhance mutual awareness and holistic understanding of the older person's health needs. These opportunities should also be used to deliver contact with the diverse meanings and goals older people have in their lives, to make providers incorporate a positive instead of deficit-oriented view of them. This is complemented by a need to avoid internalisation of negative societal stereotypes of older people that are often shaped by the perception of deficits and loss (of health, social contacts, societal recognition) and of older people being less needed in society [44]. This internalisation is a broad societal process that, for example, condenses in literature or the media [45]. Hence, reflecting on these narratives and building a more positive one could also be an effective approach.

Strengths and limitations

To the best of our knowledge, this is the first study to investigate perceptions of both ambulatory health and oral healthcare from the perspective of community-dwelling, independently living people aged 80 and over. The results enable a holistic view of health services in the ambulatory healthcare sector to help our understanding of older people's perspectives, and provide an integrative framework of what constitutes good care as a basis for the development of care models. Nevertheless, some limitations have to be taken into account. First, the study was limited to the urban area of Cologne, so the results might not be transferable to rural areas. In particular, a higher density of health services needs to be considered. Second, although we followed a purposive sampling approach, important characteristics such as migration background were not considered and might have altered the results, e.g., regarding aspects such as trust, access and costs [22].

Conclusion

A variety of characteristics shape the perception of good ambulatory health and oral healthcare from the perspective of people aged 80 and over. These characteristics should be jointly addressed in the provision of health services, especially regarding the integration of oral health matters in a holistic approach. Future research should take into account the perspective of healthcare providers to provide a better understanding of healthcare interactions and relationships and to elicit specific starting points for strengthening (older) patient-centred comprehensive healthcare.

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<u>Availability of data and material</u>: The datasets generated and analysed during the current study are not publicly available due to limitations of ethical approval involving the patient data and anonymity but are available from the corresponding author on reasonable request.

<u>Ethics committee approval</u>: The study was approved by the Medical Ethics Review Board of the Medical Faculty at the University of Cologne (19-1645).

<u>Clinical trial registration</u>: The study was registered in the German Clinical Trials Register (DRKS00020889).

<u>Research participant consent</u>: Written informed consent from every participant was obtained before the interviews.

Declaration of Conflicts of interest: None

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Tables

Table 1: Summary of interview guide

Table 2: Sample characteristics

Table 3: Original and translated illustrative interview passages

Figures

Figure 1: Overview of methodological process

Figure 2: Results concerning characteristics of desirable ambulatory health and dental care

Online Resources

Appendix A: Full list of themes

Appendix A: Full list of themes

The table provides a full overview on all analysed themes in the study.

Theme	Subthemes/codes		
Older people's views	General satisfaction with life		
of themselves and their health status	Acceptance of ageing		
	Age-related restrictions		
	Thoughts about deterioration of health		
	Altered requirements due to aging		
	Perception of other people's views on older people		
	Who takes care for me? – getting along alone		
	Who takes care for me? – external daily support		
	Who takes care for me? – daily support from family and close environment		
Older people's	General satisfaction with the healthcare system		
general perceptions and interactions	Perceived problems of the healthcare system		
regarding ambulatory health and oral	Holistic view on health		
healthcare	Reports on previous healthcare and experiences		
	Significance of healthcare		
	Motives of using healthcare – routine examination		
	Motives of using healthcare – aesthetics and well-being		
	Motives of using healthcare – preservation and functionality		
	Motives of using healthcare – bonus of the health insurance		
	Avoidance of unnecessary use of healthcare		
	Perception of other older people using healthcare		
	Role of fears and negative experiences		
	Self-management		
	Interaction of the own behaviour with the healthcare system		
Aspects of good	[General/neutral descriptions of processes]		
ambulatory health and oral healthcare	[Role of the non-physician professions]		
	Attributes of health and oral healthcare providers – Skills of Professionals		
	Attributes of health and oral healthcare providers – Friendliness		
	Attributes of health and oral healthcare providers – Continuity and Reliability		
	Patient-provider-interaction – Time for Healthcare		

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Theme	Subthemes/codes
	Patient-provider-interaction – Open and Confidential Communication
	Patient-provider-interaction – Information
	Patient-provider-interaction – Involvement in Decisions and Healthcare
	Patient-provider-interaction – Healthcare Contact as Social Contact
	Patient-provider-interaction – Personal Relationships
	The output of health and oral healthcare – Result of Healthcare
	The output of health and oral healthcare – Sufficient Support
	The output of health and oral healthcare – Costs – Different health services for statutorily and privately insured/paying patients
	The output of health and oral healthcare – Costs – Appropriateness of health services and costs
	The output of health and oral healthcare – Costs – Thoughts on Arising Expenses
	Organisation and context of health and oral healthcare – Healthcare Coordination
	Organisation and context of health and oral healthcare – Access to Healthcare – Organisation of Health Services
	Organisation and context of health and oral healthcare – Access to Healthcare – Timely Availability of Health Services and Contact Persons
	Organisation and context of health and oral healthcare – Place of Healthcare
	Organisation and context of health and oral healthcare – Practice Characteristics
	[Activation*]
Older people's core	Maintaining Control and Independence
motives** regarding outpatient healthcare	Feeling Safe
and oral healthcare	Feeling Like a Meaningful Human Being
Reports on the Covid-	Relevance in daily life
19 pandemic	Relevance in healthcare
	Protective Measures
Further reports	Reports on illness
	Reports on life
	Criticism of the system
	Reports from other areas of healthcare
	•

^{*}The characteristic "activation" was included in the prior meta-synthesis [33], but not discussed by the participants in the interviews of this study. ** Core motives identified in the prior meta-synthesis [33] and introduced in the interview guide to further explore them.

Appendix: Publication 4

Publication 4

Providing ambulatory healthcare for people aged 80 and over: Views and perspectives of physicians and dentists from a qualitative survey

Angélique Herrler, Lisa Valerius, Anna Greta Barbe, Vera Vennedey, Stephanie Stock

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Data Availability Statement: All relevant data are within the article and its supporting information files. Supplemental file S1 Appendix contains all data on the survey development and pretest.

RESEARCH ARTICLE

Providing ambulatory healthcare for people aged 80 and over: Views and perspectives of physicians and dentists from a qualitative survey

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Abstract

Background

People aged 80 and over frequently face complex chronic conditions and health limitations, including oral health problems, which are primarily addressed by ambulatory (i.e., outpatient) healthcare. This demographic development is expected to affect the provision of care. However, few studies have investigated physicians' and dentists' views across the various medical disciplines in non-institutional settings. This study investigated how healthcare providers perceive caring for very old people, and how they feel healthcare should be designed for this patient group.

Methods

A qualitative online survey comprising nine open-ended items was conducted among physicians and dentists practicing in the ambulatory healthcare sector in North Rhine-Westphalia, Germany. Apart from child and adolescent healthcare, no medical specialties were excluded. The results were analysed using Kuckartz' approach of structuring qualitative content analysis. A descriptive codebook was developed first. After coding all the material, recurring patterns between the topics were investigated and compared between two groups of participants, physicians and dentists.

Results

N=77 cases were included in the analysis, from which n=21 originated from the field of ambulatory general practice care and internal medicine, n=19 from specialties (e.g., neurology, urology), and n=37 from dentistry. Caring for patients aged 80 and over was perceived as challenging because of complex health conditions and treatments such as multimorbidity

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Supplemental file S2 Appendix contains the full codebook that was developed and used for data analysis. Supplemental file S3 Appendix contains the data obtained from participants in the qualitative survey. Since the data are of a qualitative nature, the authors provided the material only in its coded form and without sociodemographic information on case-level to ensure anonymity. Information on sociodemographic variables is included in Tables 1–2 in the manuscript.

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and polypharmacy, and patients' cognitive and physical limitations. In characterizing good care in older age, both groups found individual care important, as well as empathetic interactions and good collaboration in networks of healthcare providers. Inadequate reimbursement and limited resources and time were the most important barriers to providing good care, while one of the most important facilitators was healthcare providers' attitude and motivation.

Conclusions

Physicians' and dentists' conceptions of good healthcare are in line with the conceptualization of patient-centred care. However, the transfer in everyday care delivery is hampered by the current design of healthcare structures. Healthcare providers feel overstrained by the increasing demands placed on them. Adaptations for improvement should focus on building strong networks of cooperating health professions, especially including dental care, and local social support structures.

Introduction

Due to demographic changes, the section of the population of people aged 80 and over will grow significantly in Europe [1]. Around the age of 80 years, complex long-term health issues such as multimorbidity and frailty show a strong increase, demanding proactive healthcare [2–5] that is primarily provided in the ambulatory (i.e., outpatient) healthcare sector [6,7]. This also applies to the area of dentistry since old age is associated with a variety of oral health issues and dental treatment needs, such as dry mouth problems, periodontal disease, decreased oral function or denture-related conditions [8], while the role of oral health for maintaining the quality of life and well-being is increasingly recognized [9].

However, most healthcare systems are still criticized for being primarily oriented toward acute care that focuses on single conditions and care episodes [10,11]. Therefore, until now, responsibility for the different approaches to healthcare required by the older population has appeared to fall mainly on the micro level and on healthcare providers. This particularly affects providers in the ambulatory healthcare sector, since older people's health matters are frequently of chronic nature, and they have a strong preference for ageing in place and avoiding institutionalisation [12,13]. Moreover, strengthening ambulatory healthcare is one of the main suggestions by institutions such as the Organisation for Economic Co-operation and Development (OECD) or the World Health organisation (WHO) to meet the demands of ageing populations [14,15]. But, apart from geriatric specialisations, approaches to treatment and healthcare delivery for older patients are not yet broadly discussed in medical or dental training, possibly leading to inadequate awareness of the special needs of these patients, and to feelings of stress and frustration in healthcare providers [16,17]. Studies suggest that how professionals perceive older patients and their care has an impact on their patient interactions and satisfaction with their work. For example, it was found that nurses holding negative attitudes towards older people were stereotyping their patients, finding them incapable of decision-making and perceiving them as a burden [18,19]. This conflicts with older people's core motives in healthcare, these being 1) to feel safe, 2) to feel like a meaningful human being, and 3) to maintain control and independence [20]. Therefore, understanding healthcare providers' perceptions and their interactions is crucial for delivering appropriate healthcare to older

adults. However, studies exploring the perspectives and needs of physicians and dentists, apart from a few investigating general practitioners (GPs) [17,21], are rare. What challenges arise in the practice of caring for older adults and what support needs occur, has been primarily examined in institutionalized settings (e.g., [22–24]) or among nurses (e.g., [25,26]). Since older people are especially present in the field of ambulatory healthcare settings with their usual health matters, this poses a considerable gap in understanding the daily reality of patients and healthcare providers, and regarding what is needed to maintain or further develop a proper healthcare workforce.

Apart from understanding healthcare providers' occupational routines with older patients, insight into their interactions is needed to design patient-centred care (PCC) for older adults that is aligned to health services' reality. Moreover, since healthcare needs to be increasingly coordinated and integrated to serve the needs of complex health issues and patient-centredness, a broader investigation comparing the variety of specialisations, including dental care, seems useful. Therefore, this study aimed to provide a deeper understanding of the perspectives of the variety of physicians and dentists providing ambulatory healthcare for people aged 80 and over, to understand the challenges they face and to draw conclusions about how healthcare delivery for older adults should be organized. The focus on this specific age group was chosen because of the already described increase in complex health issues and care needs around the age of 80 years, and also to deliver more nuanced insights since most studies on older people broadly summarize them in age categories such as 60+ or 65+ years [27,28]. The vast investigation of physicians and dentists was intended to meet the requirements of a necessary development of new interdisciplinary, integrative concepts of healthcare, explicitly incorporating the neglected area of oral health and care in older age [8,11,29–31].

Accordingly, three research questions guided the study:

- 1) How is care for people aged 80 and over characterized from the perspective of physicians and dentists?
- 2) How should the delivery of health and dental care for people aged 80 and over be designed from the perspective of physicians and dentists?
- 3) What influences the provision of good care for people aged 80 and over from the perspective of physicians and dentists?

Methods

A qualitative online survey was conducted to answer the research questions. The study was approved by the Medical Ethics Review Board of the Medical Faculty at the University of Cologne (21–1152). Written consent by confirming an online tick box (mandatory to start the survey) was obtained. The study was pre-registered in the German Register for Clinical Trials (DRKS00024666). Since there is no reporting guideline specifically for qualitative surveys, reporting of the study is based on the consolidated criteria for reporting qualitative studies (COREQ) [32] and the consensus-based checklist for reporting of survey studies (CROSS) [33], as far as they were applicable to this research design. An overview of the methodological process is provided in Fig 1.

Setting

The study was performed in Germany's largest federal state, North Rhine-Westphalia, and focused on the ambulatory healthcare sector. In Germany, ambulatory healthcare is separated, regarding organisation and reimbursement mode, from the hospital care and the rehabilitation

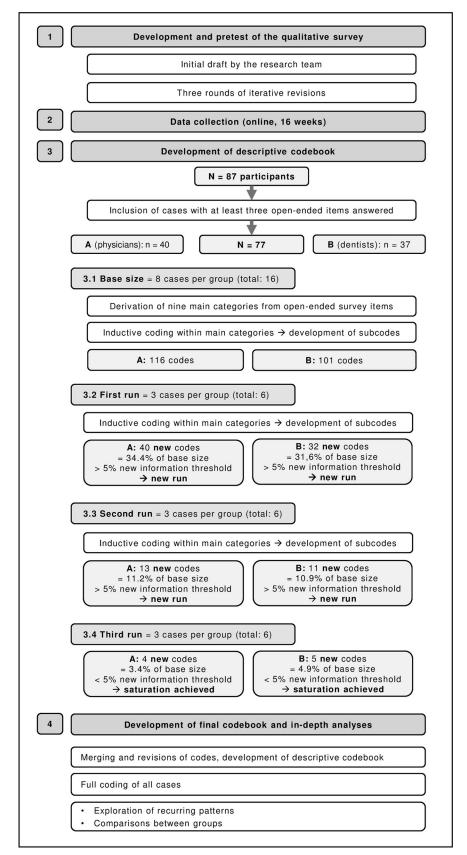


Fig 1. Methodological overview.

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sector. GPs, specialists and dentists in the ambulatory healthcare sector provide services in their private practices [34]. Most of their services are covered by statutory health insurance for nearly 90% of the population; however, private co-payments for additional services are possible [34].

Design and development of the qualitative survey

Employing a phenomenological approach, we chose a qualitative survey design, in a self-administered online mode, to answer the research questions. Apart from a few closed items, qualitative surveys primarily pose open questions following a qualitative research logic to explore the "participants' subjective experiences, narratives, practices, positionings and discourses" [35]. Qualitative surveys are useful in depicting the broader diversity of the phenomena of interest and in recruiting hard-to-reach groups; therefore, new and rich insights can be gained [35]. We chose this study design due to the breadth of the physicians' and dentists' specialisations and their usually limited availability for time-consuming qualitative studies due to their high workload. For this survey, they could flexibly choose from where and when they want to participate.

With regard to the research questions, relevant aspects and questions were brainstormed, initially. After discussion among the multidisciplinary research team (health sciences, health services research, medicine, dental care, sociology), the initial version of the survey was pretested. The pretest was based on iterative rounds of comments and revisions until the items worked as intended. This was reached after three rounds, the changes mainly concerning comprehensible wording of the items and the length of the survey. Details of the pretest rounds, the participants, and survey development are provided in an online (S1 Appendix).

The final survey contained nine closed items on sociodemographic and practice aspects. The eight open items asked for 1) characterization and challenges of working with patients aged 80 and over, 2) what constitutes good healthcare in older age from the healthcare providers' perspective, 3) influential factors (barriers and facilitators) of treating older patients as intended, 4) conceptions on ensuring that patients feel safe, feel like meaningful human beings and maintain control and independence (older people's core motives identified in [20]), and 5) proposals to improve or design future healthcare in old age. The complete survey is provided in the online \$1 Appendix.

Sampling and recruitment

Participants were eligible for the survey if

- 4) they were GPs or specialist physicians or dentists,
- 5) they practiced in an ambulatory healthcare setting in North Rhine-Westphalia, and
- 6) had sufficient reading and writing skills to answer a German questionnaire.

Physicians exclusively treating children and adolescents (e.g., paediatricians) or not practicing in an ambulatory healthcare setting in North Rhine-Westphalia were not eligible for participation.

We followed a convenience sampling strategy [36] to recruit physicians and dentists from diverse specialties but did not aim at statistical representativity. Because there are no clear guidelines for the sample size of a qualitative survey, we took the recommendations from Braun et al. as a reference point and aimed at recruiting 50–100 participants for a mid-range sample [35]. To reach the participants, 45 physician organizations (e.g., physician networks) were contacted and asked to promote the survey by spreading the survey link and a short

information text via newsletters, e-mail lists or their websites among their members. Fourteen organisations agreed to spread the survey.

Data collection and analysis

The survey was created via SoSciSurvey. The participants were informed about all aspects of anonymous data processing and had to actively agree to participate to start the survey. The final dataset was transferred to MAXQDA Analytics Pro 2020 (Verbi software, Berlin). Cases were included for analysis if at least three open-ended items were answered.

The closed items were analysed descriptively. For the open items, we followed the approach of structuring qualitative content analysis designed by Kuckartz in developing a descriptive codebook [37,38]. Moreover, to increase transparency and assess whether data saturation could be reached within our sample, we decided to document the development of thematic saturation (little or no new information in additional cases regarding the research question) [39]. We set the base size at 16 cases (eight from Group A–physicians, and eight from Group B–dentists) for defining the initial body of information, and a run length of six cases (three per group) to define additional information. We set the new information threshold at \leq 5% (new themes found within a run compared to the base size) [39]. Therefore, new runs were analysed until the new information threshold was reached.

Following Kuckartz, the main categories were derived from the open items first. Second, two researchers (AH-health scientist, LV-sociologist, both female) independently read, memo-ed and inductively coded the first randomly chosen eight cases per group line-by-line and structured the results towards a first set of subcategories per main category. Both researchers discussed their results and agreed on a joint set of categories that was described in a codebook. Next, this was repeated with the first run of cases, in which newly identified codes were highlighted. After discussion, the codebook was revised accordingly. The procedure was repeated until the new information threshold was reached. Third, the codebook was reviewed and discussed by the research team. Subsequently, AH fully coded the remaining cases and the coding was checked by LV. The coded survey data was then examined regarding mutual patterns among the categories and compared between the two groups. The participants from the survey were not included in the data analysis process.

Results

Data were collected from October 2021 to February 2022. In total, there were 87 participants. In n = 77 cases, at least three qualitative answers were provided and, therefore, they were included in the analysis. Both groups were comparable regarding demographics (Table 1). Most participants were aged between 50 and 60 years and male. Professional practice experience ranged from four to 44 years (mean 23 years). Nearly all the participants indicated they worked in an urban or mostly urban region. Most respondents stated that the proportion of patients aged 80 and over in their practice comprised up to 25%, and the vast majority had the perception of having received good education and training regarding caring for older adults. Approximately one third stated they were able to provide the care as desired in 75% or more of their cases, while 22 participants stated this applied to 49% or less of their cases (Table 2).

Thematic saturation was reached after three runs of independent code development. In the following, the results will be described in the broader themes identified throughout the different topics addressed in the survey: 1) characteristics of providing care for older people, 2) what matters to good healthcare in older age, 3) barriers and facilitators in the provision of good care. An overview of the topics is provided in Fig 2. The descriptions are based on the more detailed codes developed during analysis, which are depicted in Table 3. Moreover, the

Table 1. Participant demographics.

		Total	Physicians (n = 40)	Dentists (n = 37)
Age	30-39 years	9	3	6
	40-49 years	6	2	4
	50-59 years	31	18	13
	60-69 years	27	14	13
	70-79 years	4	3	1
	missing	-	-	-
Sex	male	51	27	24
	female	25	13	12
	missing	1	0	1
Professional experience	mean/median (range)	23/24 (4-44)	21/22 (4-40)	24/25 (5-44)
	missing	2	2	0
Specialization	general practice/internal med	general practice/internal medicine		-
	internal medicine, geriatrics	internal medicine, geriatrics		-
	internal medicine, 'no' or 'oth	internal medicine, 'no' or 'other' focus than geriatrics		-
	surgery	surgery		-
	otorhinolaryngology	otorhinolaryngology		-
	neurology	neurology		-
	nuclear medicine	nuclear medicine		-
	physical and rehabilitative me	physical and rehabilitative medicine		-
	anesthesiology	anesthesiology		-
	urology	urology		-
	dentistry with focus on geriat	dentistry with focus on geriatric dentistry		7
	dentistry with other focus of a	dentistry with other focus of activity		9
	dentistry without focus of activity		-	21

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codebook, including example interview passages (German original with English translation), is provided in online S2 Appendix and the full coded material from the open items (German original) is provided in online S3 Appendix. Passages from interviews are labelled with GP for general practitioners, S for specialists and D for dentists.

Characteristics of providing care for older people

The complexity of multimorbidity and polypharmacy. The participants, especially the physicians, referred to older patients' health status mainly as complex and limited and, consequently, challenging. In particular, they described multimorbidity and polypharmacy, causing more intensive care and time effort, limitations of mobility and care options, special attention regarding adverse events, and also the perception that older people themselves feel overstrained or helpless because of their medical complexity. It was further described that most disease-specific guidelines did not consider complex conditions such as multimorbidity or frailty and, therefore, were not useful in these situations. These circumstances were described as particularly challenging because it was often difficult to determine "a reasonable scope of diagnostics and therapy" (S-516, §5).

Physical and cognitive restraints influencing treatment and communication. Older adults' physical and cognitive limitations, often influencing interactions and treatments, were also frequently noted in both groups. Cognitive restrictions such as limited sensory perceptions (hearing, seeing), slowness and forgetfulness were explained as challenging for

Table 2. Results of closed items.

		Total	Physicians	Dentists
Estimated proportion of privately insured patients in the practice	<10%	33	17	16
	11-25%	34	19	15
	26-40%	5	3	2
	41-65%	4	0	4
	66-79%	0	0	0
	>80%	1	1	0
	missing	0	0	0
Estimated proportion of patients aged 80 and over in the practice	<10%	16	7	9
	11-25%	44	22	22
	26-40%	10	6	4
	41-65%	4	3	1
	66-79%	3	2	1
	>80%	0	0	0
	missing	0	0	0
Perception of having received good education and training	yes	40	20	20
	rather yes	33	19	14
	rather no	4	1	3
	no	0	0	0
	missing	0	0	0
Perception of providing good care (estimated proportion of all treated cases)	<25%	8	2	6
	25-49%	13	8	5
	50-75%	30	16	14
	>75%	26	14	12
	missing	0	0	0

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communication. In general, a dominant description was how communication with older patients was more demanding. This was explained by the limited capacity to understand and remember complex information and more questions, and a need for information: "Difficulties in communication–patients absorb less information and cannot express themselves that well anymore" (D-189, §17). Moreover, it was mentioned that communication also needed to cover psychosocial needs more strongly compared to younger age groups. Therefore, more time and adapted communication styles (e.g., reducing complexity, speaking clearly) were required. Additional time was also needed because of more complex treatment planning as well as to exchange information with other disciplines and stakeholders, according to both groups. Many of the participants believed they did not have the time to implement these approaches.

Physical limitations such as impaired mobility or declined motor skills were also described as demanding alternative concepts of treatment, e.g., including more breaks during the consultation or treatment. This was particularly reported by dentists, who could often not tilt older patients in the dental chair during treatment because of cardiovascular diseases, stiffness, and dizziness.

In contrast, six participants stated that older patients appeared to be heterogeneous, with some still being fit and self-determined and not causing any additional effort.

Unclear or conflictual care planning. In both groups, the participants described that some older people accepted their health status as normal due to their age and that they held the view or were unsure whether treatment would still be worth it. Conversely, some physicians stated that older people held unrealistic views of their health status and the possibilities

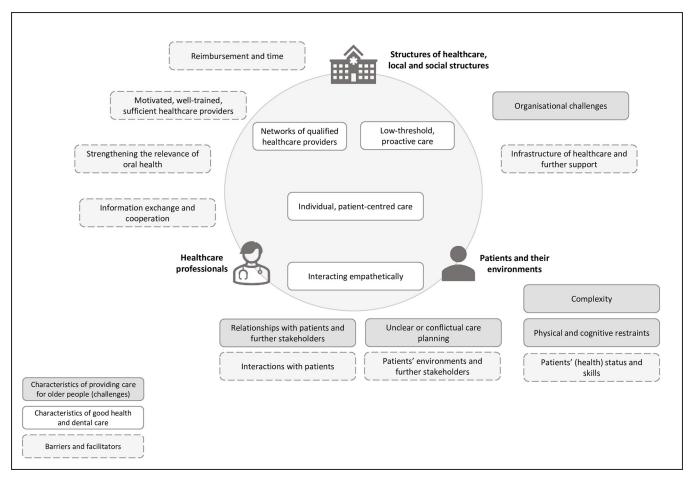


Fig 2. Overview of results.

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of diagnostics and treatment. Concomitantly, conflicting views on older people's compliance were outlined. On the one hand, especially GPs had the perception that older people were more paternalistic-oriented and more compliant. On the other hand, a lack of compliance and resistance to advice were also described, sometimes characterized as "stubbornness" (S-217, §10). Regardless of the cause, it was described that non-compliance increased physicians' and dentists' expenses.

Older patients' care goals and non-medical concerns were perceived as challenging; this was most dominantly described by GPs. The first challenge on this matter was that reasonable treatment was not always clear, nor were patients' individual goals, which could differ from the physician's or dentist's views. Moreover, psychosocial concerns such as loneliness, lack of familial or social support, financial problems and the organisation of support were described as additional demands on healthcare. The participants found themselves confronted with these demands, which could be of relevance in providing a good care plan, but likewise, several did not perceive it as their area of competence or could not provide the resources necessary for fulfilling them, e.g., due to limited time.

Organisational challenges. As a result of the more complex care situation, treatment concepts were described as being more individualized and frequently incorporating "the solution of daily problems and organisational regards" (GP-253, §5). Sometimes, the organisation of social or specialist services was considered a part of the treatment concept. The dentists also

Table 3. Overview of descriptive codebook and code frequencies.

Main category (number of cases answering)	Subcategories/codes	No. of cases coded among physicians*	No. of cases coded among dentists*
Characteristics of working with people aged 80 and over (n = 76)	Role of life and experiences	2	1
	Positive attributes	8	6
	Challenging attributes	15	4
	Complexity due to multimorbidity and polypharmacy	12	7
	Physical and cognitive limitations	19	20
	Heterogenous appearance	3	3
	Higher need for care	0	3
	Perspective of people aged 80 and over regarding their health and care	7	6
	Paternalistic orientation	4	0
	Discernment and compliance	3	4
	Relationship-building and trust	4	3
	Speed and time	20	11
	Continuity and control	2	2
	Need for support	2	1
	Additional stakeholders and actors	7	6
	Communication	9	10
	Treatment concepts	6	11
	Structural and organizational specific features	4	5
Good healthcare in old age	Individual, person-centred view and care	15	10
(n = 75)	Status and behaviour of patients	3	2
	Patient-relevant outcomes	12	12
	Empathy and appreciation	4	4
	Communication	6	2
	Time	11	7
	Proactive care	9	18
	Access and infrastructure	13	10
	Sufficient and well-trained staff	3	5
	Cooperation with further actors	5	5
	Patients' environments	5	2
Challenges in caring for people aged 80 and over	Complexity due to multimorbidity and polypharmacy	13	7
(n = 73)	Influence of physical and cognitive limitations	14	15
	Lack of compliance or rejection of treatment	8	4
	Handling of time resources	10	7
	Relatives and further actors	3	10
	Patients' care goals and (non-medical) further issues	10	3
	Structural and organizational challenges	9	9
	No challenges	1	1
Descens for not providing the desired core		7	22
Reasons for not providing the desired care (n = 72)	Patients' (health) status and abilities Patients' environments and further actors	11	7
··· /-/			
	Lack of compliance or discernment Financial Reasons	2	9
		2	16
	Expenditure/lack of time	11	3
	Lack of information exchange and cooperation with other actors and disciplines	4	5
	Lack of (qualified) staff	5	1
	Bureaucracy	2	1
	Design of healthcare infrastructure	8	7

(Continued)

Table 3. (Continued)

Main category (number of cases answering)	Subcategories/codes	No. of cases coded among physicians*	No. of cases coded among dentists*
Facilitators of providing good care	None	0	1
(n = 70)	Care providers' experiences	5	3
	Care providers' qualifications and training	7	6
	Care providers' attitudes and motivation	19	13
	Encounters with patients	13	4
	Patients' (health) status	2	2
	Interactions with further stakeholders	12	8
	Time	4	1
	Interdisciplinary cooperation	7	1
	Local structures and offers	4	1
	Supporting tools and programmes	4	0
Ensuring a feeling of safety	Not possible	1	0
(n = 71)	Familiar environment	2	2
	Timely contact options	4	1
	Proactive care	2	3
	Support	5	6
	Good communication, counselling and conversations	17	7
	Attention and appreciative behaviour, relationship-building	12	19
	Sufficient time	1	5
	Competence and education	2	3
Ensuring a feeling like that of a meaningful	Not possible	1	0
numan being	Good communication, counselling and conversations	4	7
(n = 72)	Attention and appreciative behaviour, relationship-building	25	19
	Sufficient time	9	6
	Engagement with individual needs and wishes, holistic view	8	9
	Social integration	4	0
Ensuring the maintenance of control and	Not (always) possible	3	1
ndependence	Engagement with individual needs and wishes, holistic view	1	2
(n = 65)	Good communication and counselling	5	3
	Appreciative behaviour	1	3
	Enabling decision options	6	6
	Encouragements and support without paternalism	5	5
	Maintaining and expanding functionalities, prevention	11	1
	Structures of support and care	15	5
Measures to improve healthcare in old age	Prevention orientation	3	4
n = 67	Patient orientation	6	2
	Empathy	2	2
	Reimbursement	16	12
	More time	10	4
	Access	2	4
	Support structures	15	10
	Information exchange and interdisciplinary cooperation	5	4
	Simplification	0	2
	-		
	Qualification and training More (qualified) staff	3	7
	More (qualified) staff	5	3
	Consideration of non-medical dimensions	8	1

^{*} The frequencies are shown to provide more transparency and insight into the findings but are not appropriate for drawing conclusions based on their weighting or importance.

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highlighted how they focused their treatment concepts on reduced therapy, uncomplicated handling and, particularly, on the absence of pain.

Moreover, participants in both groups described that for older patients, more effort regarding the organization of (social) support and transport had to be made. One of the most important challenges was that necessary ambulatory and local support structures decreased and were more cumbersome to obtain. Specialists and dentists also complained about a lack of information and the necessary equipment to adequately treat older patients. The lack of information was further explained by missing medical reports and information from other disciplines. Moreover, care at home was perceived to be difficult to ensure due to bureaucratic and financial hurdles, especially when "the financial means of the older person are depleted" (GP-525, §8). Dentists also pointed out that providing dental care was difficult because staff and equipment needed to be transported and cooperation with the nursing home staff was sometimes bad.

Relationships with patients and further stakeholders. Some participants stated that caring for older adults often means building relationships over many years, resulting in deep trust. This was also mentioned as a demand of the older patient group, which was described to be "happy to receive personal attention, a conversation away from the condition" (GP-198, §3) and sometimes needed special sensitivity.

In both groups, it was noted that the entire care situation changes when relatives or caregivers accompany the older patient. This could be perceived as helpful, but they were also stakeholders with their ideas and demands, resulting in additional expenditure of time. This was explained by sometimes differing own interests and goals of these people, as well as "utopian demands" (D-374, §3). It was also found that consultations with relatives and formal caregivers could be complicated and bureaucratic, e.g., regarding cost coverage of necessary treatments such as dentures.

Good healthcare in older age-what matters?

Treating a person, not a case: Individual, patient-centred care. Providing an individual, patient-centred view and treatment was a dominant feature of good healthcare in older age for both groups and considered very important when addressing older patients' core motives. This was described as ensuring "individually adjusted therapy concepts, less guideline medicine" (S-232, §4) and adapting the care plan to the patients' individual wishes, circumstances, functionalities, and treatment goals. The most important goal explained in this regard was maintaining independence and autonomy as best as possible, including mobility and functions such as chewing. Moreover, maintaining quality of life, guaranteeing freedom from pain, and providing prevention and control-oriented care were also found to be important. Balancing risks and benefits-oriented towards patients' functionalities and feasibility were described, as was the necessary courage to provide less treatment and medication. Moreover, focusing on mental health and well-being as well as inquiring about the patient and listening well ("narrative medicine") were mentioned.

Motivating patients to maintain activities and preventive measures, and to use early interventions if functions were declining were highlighted to support their maintenance of control and independence, as well as encouraging them to accept support, to engage in improving functions and recommending supportive measures without paternalism. Pointing out different treatment options and providing good counselling to them and, therefore, enabling the scope for decision-making were reported to strengthen patients' self-esteem and autonomy.

Interacting empathetically without time pressure. For a range of cases in both groups, communication was important in providing good healthcare. This was primarily described as

listening patiently, paying attention, and addressing questions and concerns comprehensively to provide good counselling and comprehensible explanations. Therefore, "granting sufficient time" (D-454, §12) and acting empathetic, appreciative, respectful, and friendly were considered necessary. In both groups, taking sufficient time for the interaction was particularly considered to make the patients feel safe and meaningful. Good communication, counselling and conversations were also among the most important aspects to address all three older patients' core motives and build trustful relationships, incorporating interactions on an equal level and respect for the older patients' life's work.

In contrast, three GPs and two dentists also mentioned that the interaction and therefore, healthcare, is good when patients are compliant and have realistic expectations.

Providing low-threshold, proactive care. A very important feature in both groups, but disproportionally often described by dentists, was proactive care. Proactive care was described as providing reliable and continuous examinations and check-ups, strongly connected with broader offers of prevention (e.g., regarding mobility and dental prophylaxis) and dental hygiene (possibly with help) to maintain independence. Moreover, involving relevant people such as relatives or caregivers in planning care was considered proactive care. Some dentists additionally referred to enabling manageable care as well as long-lasting prostheses.

Access and infrastructure were also a feature of good healthcare in both groups, but especially dominant among the specialists. This aspect included medical and dental care located nearby or, alternatively, the availability of low-threshold opportunities for transport to reach a practice. Moreover, access and provision of further offers such as "social assistance, networks, ambulatory support" (S-470, §4) were described regarding this. Especially, physicians referred to ensuring these structures to address older patients' motives to maintain control and independence, including the accessibility of information and optimisation of living and care facilities. Furthermore, ensuring support regarding medication intake, the involvement of relatives, and enabling the use of aids and restorative measures, were suggested to help address older patients' core motives.

Another important aspect was low-threshold access to necessary therapies and diagnostics, as well as preventive examinations, without bureaucratic or financial barriers (e.g., cost coverage by insurances): "The semi-annual check-up is important because motor skills decline and the oral hygiene is not ensured sufficiently anymore" (D-439, §6). Additionally, timeliness and continuity of care, sufficient (specialist) physicians and accessibility were mentioned.

Networks of qualified healthcare providers. Another aspect discussed under good healthcare was the availability of sufficient well-trained staff. Participants referred to broadly trained professionals, who are aware of the necessary aspects of caring for older patients. They also explained that healthcare providers' perceived competence would make the patients feel safe. Moreover, the "close cooperation of all professional actors" (S-516, §4), such as medical professionals, nurses, caregivers, and social services, was proposed to enable holistic care and comprehensive, individually shaped support for patients. Three dentists also mentioned cooperation with nursing homes to provide good oral healthcare and hygiene.

Barriers and facilitators in the provision of good care

Patients' (health) status and skills. Older patients having bad overall (health) was described as a barrier to providing care as desired, predominantly by dentists. It was held that physical limitations, namely decreased resilience, bone loss and limited motoric skills, made the desired treatments difficult to impossible. Moreover, multimorbidity and polypharmacy leading to medical complexity and an unstable overall health status hampered the desired treatments. Concomitantly, good overall health and functionality in the patients were described as facilitators by some participants.

A lack of skills and functionalities necessary to master daily life, as well as private or social barriers regarding support or financial resources, were also discussed as ultimately negatively influencing patients' health status and, therefore, medical or dental treatment. Additionally, bad cognitive functioning and dementia were mentioned by some participants as barriers to cooperation. Consequently, a stronger prevention orientation was described as necessary: "make provisions at a young age, to need medical help as little as possible in old age" (S-499, §13). While physicians focused on cultivating a health-promotive lifestyle early in life, dentists rather focused on offers and coverage of dental prophylaxis and preventive routine examinations.

Patients' environments and further stakeholders. Patients' environments, including further stakeholders such as relatives, were also mentioned as possible barriers to providing the desired care, especially by GPs. A lack of acceptance of patients' wishes, lack of support or discernment by relatives and formal caregivers, as well as "a too high and counterproductive sense of entitlement" (GP-245, §7) were described as impediments to good care. However, the involvement and support of relatives and caregivers were mentioned as a possible facilitator as well. This could be achieved by meaningful exchanges with them and additional support to make good decisions for the patient.

Interactions with patients. In both groups, but most dominantly by GPs, meaningful interactions with the older patients were mentioned as facilitators. "Intensive conversations" (GP-202, §19) and patients' gratitude were perceived as being supportive. Moreover, the patients' cooperation and their stable social environments were also described as supportive. Consequently, focusing more on the patients as individuals and granting them dignified and respectful care were described as necessary measures to improve healthcare. On this matter, narrative medicine was highlighted as a principle that should be supported by the organisation and reimbursement of the healthcare system.

However, a lack of patient compliance was described as hindering the desired care, especially by GPs. Physicians explained this factor as patients lacking discernment in the necessity of treatments, stubbornness and not adhering to treatment plans. Some dentists described that there might be discrepancies between the patients' wishes and their perception of adequate treatment and, therefore, the latter would not be provided.

Reimbursement and time. A lack of time to care for and interact with older patients as desired was mentioned in both groups, more dominantly by physicians, and especially against the background of greater demand on time, as already described. Consequently, the most important measure suggested was the reorganization of reimbursement: namely, providing higher renumeration for health services in general or, in particular, for older patients. In general, it was described that it would be desirable to receive more renumeration for greater efforts regarding time spent and to enable narrative medicine, which would otherwise be hardly or not possible at all. Moreover, cost coverage for further or necessary therapies and treatments such as prophylaxis, oral hygiene, physiotherapy or occupational therapy were found necessary. Especially dentists described how desired care depended on the "patients' [limited] financial resources" (D-399, §8).

Information exchange and cooperation. Specialists noted that one reason for not providing the desired care was "a lack of information and cooperation" (S-516, §7) and the absence of complete medical records to adequately treat their patients. Moreover, the specialists and dentists explained that cooperation with other disciplines and actors was needed to provide comprehensive and good care, but that their availability was often limited, communication was lacking, and that they also perceived a lack of willingness to cooperate. In particular, the specialists valued the exchange with colleagues and cooperation with other disciplines involved in the care of the older patient as a facilitator, as well as having a professional network. In both

groups, better interdisciplinary cooperation and networking among all care providers were explicitly requested.

Motivated, well-trained, and sufficient healthcare providers. One of the most important facilitators described in both groups was the attitude and motivation of medical professionals. To provide good care despite the described obstacles, it was explained that idealism and engagement, as well as empathy and a strong moral claim to supporting older patients and guaranteeing them the healthcare they deserve were facilitating. It was also mentioned that the participants thought of their own future as being old or "my older parents" (GP-198, §10) and the care they would like to receive. Moreover, the motivation, the attitude towards older patients and "routinely well-organized team[s]" (D-384, §8) were mentioned as important facilitators, as well as their professional experience in providing health or dental care for such patients. On-going qualification and training regarding the specialties of caring for older patients was additionally described as being supportive in providing good care. However, in both groups, the participants mentioned a lack of qualified staff as a barrier, and several suggested the recruitment and education of further qualified staff.

Strengthening the relevance of oral health. Several dentists highlighted the necessity to raise awareness of the relevance of oral health in older adults among relatives, physicians and further actors. This included the integration of oral health matters and provision or support of oral hygiene, especially in care-dependent older adults, in education and training of medical staff, nurses and relatives. Moreover, broader possibilities and the cost coverage of prophylaxis in old age and support for visiting dental care were demanded. It was stated that "the dental care in nursing homes has been structurally secured in the past years—the ambulatory care still is a broad field" (D-451, §25–26). Finally, dedicated dental care rooms for visiting dentists in nursing homes were suggested.

Infrastructure of healthcare and further support. In both groups, the design of healthcare structures was discussed as an important factor in providing the desired care. This concerned a lack of cost coverage by insurance schemes, lacking therapy places, and "ageappropriate transportation systems" (S-175, §8). Moreover, a lack of possibilities to provide home and nursing home visits was mentioned. Improvement of access was described as necessary, especially regarding cost coverage and the simplification of application for treatment and therapies, home visits and preventive appointments.

Moreover, low-threshold opportunities for support structures such as ambulatory services, "patient guides that take organisational tasks" (GP-158, §16) or welfare centres were suggested. Provision of barrier-free information, help in mobility and transport, daycare centres and visiting or mobile health and dental care were said to be necessary. Therefore, a good local infrastructure of social services and ambulatory care services were said to be facilitators of good healthcare. Support structures, such as local networks guaranteeing social integration and participation in cultural activities to prevent loneliness, were also required to serve older patients' psychosocial well-being.

Discussion

This qualitative survey investigated the views of physicians and dentists on caring for people aged 80 and over in the fields of ambulatory health and dental care. We comparatively described how physicians and dentists characterize these care interactions, what they perceive to be good healthcare in older age, and which factors influenced this. The identified themes are closely interrelated, evidenced by certain factors occurring frequently in various roles. For example, "more time needed" is a characteristic of caring for older adults, while "too little time" is a challenge and a barrier to providing good care. Meanwhile, "having sufficient time" is a characteristic of and facilitator for good care.

Overall, our results show that caring for people aged 80 and over is challenging for physicians and dentists due to inherent complexity, a decline in health status, or physical and cognitive limitations that influence treatment possibilities and communication. Moreover, the entire care situation seems to have changed in caring for older adults due to 1) the mentioned complexity and, therefore, less obvious or fewer possible treatment options, 2) the older patients' genuine view on the desirability and value of treatments, 3) the greater relevance of the patients' social and local surroundings since support is needed, and 4) further stakeholders, such as relatives or caregivers, who need to be considered in care interactions and who often bring their interests and demands.

These findings are in line with a study by Zwisen et al. investigating GPs' views on complex older patients in the Netherlands [17]. Caring for complex or older patients means that direct and established strategies for providing care, as are also depicted in guidelines for single conditions or the certainty of being only in charge of a medical issue, do not work properly. This is also mirrored in the frequent complaints regarding older patients' lack of compliance or the refusal of treatment in our survey–something does not work as intended, and this puts stress on the healthcare providers.

For both physicians and dentists, good care for older people was characterized by the provision of individualized concepts, empathetic interactions and low-threshold, proactive care in a network of qualified healthcare providers. Therefore, their perceptions are in line with those of older patients, [40,41] and conceptualisations of PCC [42,43]. However, this ideal is currently hampered by insufficient time and unhelpful reimbursement structures, and the fragmentary infrastructure of healthcare and further social services. This is supported by the considerable proportion of participants stating that they were able to provide the care they found appropriate in 49% or less of their cases. In a study that externally rated PCC in consultations, it has also be shown that PCC is currently moderately apparent [44].

Consequently, the wish and the demand to provide PCC seem to be given, but this stands in contrast to the limited resources and opportunities, possibly resulting in the reported feelings of overload or frustration. Therefore, the assumption that healthcare providers primarily stem the challenges of the demographic shift in healthcare while the healthcare system does not provide adequate support seems confirmed. According to a study among GPs by Herzog et al., there are three ways GPs can manage these demands and this complexity: 1) by focusing on medical expertise and not seeing themselves in the position to serve all demands; 2) by holding a holistic view, trying to serve all demands using great individual effort; 3) by seeing oneself as one part of a broader (social) network that overall serves the demands [21]. The last strategy seems to be the most promising for physicians and dentists in the light of our results since the most frequent suggestion, besides improved reimbursement and more time, was the development and low-threshold access to further support structures, including social or welfare services.

Therefore, future efforts to design PCC suitable for the older population should focus on creating broad networks of a variety of medical providers, but not being limited to them. It was also a striking finding that relevant healthcare areas, such as dentistry, are widely unrecognized according to the dentists in our survey, who frequently complained about a lack of awareness regarding oral health and hygiene among healthcare providers, patients and relatives—resulting in a bad oral status. This finding is in line with several other studies [45–49]. Moreover, while care contacts among older people have increased in most areas of ambulatory healthcare due to increased demand, care contacts in dentistry have declined in patients in older age [50]. Therefore, the dentists demanded an increase in awareness and, in particular, a prevention-oriented care organisation.

In contrast to the current healthcare structures, which were mainly described as hindering, the most important facilitators described by physicians and dentists were their own and their staff's motivation, a positive attitude towards older people, and sufficient professional experience. While training and early exposure are frequently suggested measures [21,51], the participants in this survey valued training as a facilitating factor, even though they stated they felt well-educated themselves. Therefore, courses addressing the handling of complexity and focusing on motivation and attitudes regarding caring for older adults might be more promising than knowledge-based education. This is supported by studies among nursing and medical students which found that correcting false beliefs about older people, focusing on empathy-building and enhancing a better understanding of the ageing process made them more positive about and confident in treating older patients [16,18,19,52–55]. To support the building of care networks and strengthen a comprehensive understanding of the very old patient, broadly including the relevant areas for maintaining autonomy and well-being, this training could be provided in an interdisciplinary setting.

Possible influence of the COVID-19 pandemic on study results

This study was conducted between October 2021 and February 2022, thus, during the ongoing COVID-19 pandemic. Studies show that in Germany, especially during the first phase of the pandemic in the beginning of 2020, the legislative protection measures affected healthcare utilization. Approximately one third of a representative sample of the general population stated to have a medical, dental or therapeutical appointment postponed or cancelled (by themselves or the providers) [56]. This mostly regarded preventive and routine examinations, especially in dental care [56,57]. However, decreases were especially seen among people aged 35 years or younger and in the field of GP care, while specialist consultations, particularly among people aged 75 or 80 and over, remained stable [56-58]. In the course of 2021, a general stabilization of ambulatory healthcare utilization occurred, despite on-going or relaunched legislative protection measures [58,59]. Apart from the partially volatile patient numbers, healthcare providers were facing an additional burden especially due to diagnosis and treatment of COVID-19 in ambulatory healthcare practices, increasing alternative modes of consultation such as telephoning, infection protection measures in the practice and increased social tensions or deteriorated working climate [57,59,60]. Hence, what do the pandemic circumstances mean for the study in hand? Initially, we aimed to pose a question in the end of the survey to investigate whether the participants themselves had the impression their experiences or views had changed during the pandemic: Reflecting briefly on your previous answers, has the corona pandemic changed your views and if so, how? However, based on our own previous experiences with such questions in other qualitative studies during the pandemic [61,62] and also no meaningful results during the pretesting, we decided to delete the item after pretest round 2 (see S1 Appendix). This was also decided due to the survey questions being kept in a general manner and under the impression that the pandemic situation in the end of 2021 had started to normalize, which is at least partly supported by the available studies on ambulatory healthcare. To see whether the participants themselves raised any pandemic-related topic, we cross-searched the data set and only found three statements: 1) a GP reporting that in "normal" (non-pandemic) times, a practice assistant is supportive in caring for older people, 2) a dentist reporting that due to the pandemic, access to nursing homes became difficult, and 3) another GP reporting that due to the discourse on vaccinations, there was more distrust in the doctor-patient-relationship (see pages 9, 36, 51 in S3 Appendix). Hence, the pandemic did not seem to play a considerable role for this survey, despite potentially more persons might have participated if their workload was lower. However, it is possible that the participants' views are

under the impression of the overall additional burden and a general discourse on older people's vulnerability in the pandemic.

Strengths and limitations

To the best of our knowledge, this is the first qualitative study investigating the various medical disciplines in the field of ambulatory healthcare for very old people. The results provide a comprehensive insight into the structures and disciplines that are expected to interact in providing good health and dental care. The use of a qualitative survey was a useful data collection method since it is open and flexible enough to gain qualitative insights, but also reaches a broader target group and, therefore, exploring greater heterogeneity is possible [35]. Another strength of the study is the thorough pretesting to ensure that the unobserved data collection worked well [35], and the development of codes using transparent reporting on the development of saturation to allow for an appraisal, whether sufficient reports could be collected or not.

However, some limitations should be kept in mind. First, despite the broad target group, not all the specialities of the medical field were represented in the sample, the sample mainly consisted of male participants aged 50 and older with considerate experience in practice, and the sample was located in an urban or mostly urban environment. This limits the transferability of findings to other contexts or groups. Moreover, due to the sampling strategy, possibly only people who were interested in the topic or who had strong opinions were willing to participate. Since the recruitment strategy was not personalized and used broad ways such as advertisement on the recruiting organisations' websites, it could not be assessed how many eligible persons were reached, and consequently, no response rate could be determined. Additionally, it was theoretically possible to participate more than once. However, this seems unlikely due to the qualitative nature of the study, and since the answers were not weighed and the heterogeneity was probably greater in this survey than in other, smaller sampled types of qualitative studies, the range of views still appears to be a reasonable representation.

Second, the qualitative survey method does not allow for interactive inquiries. Therefore, the results should be seen as descriptive, with explanatory approaches, rather than as solidly theory-generating. In future studies, a combined approach, e.g., a qualitative survey followed by a small number of additional interviews to provide more depth in explanatory approaches, could be promising.

Conclusion

Providing ambulatory health and dental care for people aged 80 and over poses special challenges to physicians and dentists. There is an apparent willingness to provide PCC as a means of delivering good healthcare to older people, but doctors feel overstrained by the patients' demands and limited in their scope of action by an ill-equipped system. Efforts to reorganize the structures should focus on building networks with low-threshold access to different providers serving older patients' demands, and education for healthcare professionals should focus on handling complexity and creating positive attitudes towards the patients. Moreover, awareness of older people's oral health and a broader offer and coverage in providing dental care and hygiene in this age groups need to be strengthened to realize comprehensive care.

Supporting information

S1 Appendix. Survey development, pretest report and final survey. (PDF)

S2 Appendix. Full codebook with example interview passages. (PDF)

S3 Appendix. Full coded material from the open items. (PDF)

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Curriculum Vitae

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Übersicht der Publikationen:

- 1) Angélique Herrler, Helena Kukla, Vera Vennedey, Stephanie Stock. What matters to people aged 80 and over regarding ambulatory care? A systematic review and meta-synthesis of qualitative studies. *European Journal of Ageing* 19, 325–339 (2022). https://doi.org/10.1007/s10433-021-00633-7
- 2) Angélique Herrler, Helena Kukla, Vera Vennedey, Stephanie Stock. Which features of ambulatory healthcare are preferred by people aged 80 and over? Findings from a systematic review of qualitative studies and appraisal of confidence using GRADE-CERQual. *BMC Geriatrics* 22, 428 (2022). https://doi.org/10.1186/s12877-022-03006-6
- 3) Angélique Herrler, Helena Kukla, Anna Greta Barbe, Vera Vennedey, Stephanie Stock. Characteristics of desirable ambulatory health and oral healthcare from the perspective of community-dwelling people aged 80 and over A qualitative examination. *Age and Ageing* 51(11): afac258 (2022). https://doi.org/10.1093/ageing/afac258
- 4) Angélique Herrler, Lisa Valerius, Anna Greta Barbe, Vera Vennedey, Stephanie Stock. Providing ambulatory healthcare for people aged 80 and over: Views and perspectives of physicians and dentists from a qualitative survey. *PLoS ONE* 17(8): e0272866 (2022). https://doi.org/10.1371/journal.pone.0272866

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A. Heurel

Angélique Herrler