

Visibility and meanings of partnership in health care for older people who need support to live at home

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Introduction: Problems experienced by older people with complex needs to live at home have been reported in the literature. This qualitative study builds on previous research and investigates enduring issues older people face when interacting with healthcare services.

Aim: To gain an in-depth understanding of what is involved in providing good quality health care for older people who need support to live at home.

Methodological design: We adopted an interpretive descriptive approach and conducted semi-structured interviews with older people (n = 7), carers (n = 8) and key informants (n = 11). Initial and secondary analysis of qualitative data was completed.

Findings: Major themes emerged about meanings of partnership in health care, and invisibility of the older person as a partner in health care. Partnership in health care

was understood to mean being treated as an equal, being involved in decision-making, and making contributions which impact on health care and health systems. The metaphorical concept of ‘invisibility’ related to the older person not being seen and heard as a partner in health care, as well as being a recipient of care.

Conclusions: We concluded that older people who need support to live at home are not highly visible to health providers, policymakers and researchers as a central partner and consumer to be meaningfully engaged in shaping their health care. Opportunities to address persistent issues with quality of health care may in future be achieved through stronger partnerships between older people and health providers, to find new ways to improve the quality of care for older people.

Keywords: aged, caregivers, consumer partnerships, decision-making, home care services, person-centred care, personhood, qualitative research, quality of health care.

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Introduction

The experiences and roles of older people within the healthcare system are important areas of focus for health providers, policymakers and researchers seeking ways to improve the quality of health care for older people. Persistent issues for older people with complex needs have been reported such as unmet psychosocial needs (1, 2); poor accessibility to mental health services (3); difficulties in detection and prevention of elder abuse (4); and poor responsiveness of care in all settings for people living with dementia (5–7). Recognising the highly complex nature of such issues, qualitative explorations can provide insights informing future improvements in care for older people who may have diverse physical,

psychological and social needs. The drive to improve the quality of health care for older people who need support to live at home is motivated by respect for the inherent worth and dignity of older people (8). Failures by health providers to adequately support the needs and preferences of older people may equate to failures to uphold the dignity and rights of citizens into their later years of life. Senior managers and politicians interviewed in Sweden, Finland, Denmark and Norway expressed that the dignity and worthiness of people are an essential focus for health providers and policymakers to provide optimal future care of older people (9).

In Australia, increasing demand for health and aged care services to support older people to live at home is anticipated (10). Many older people live independently without requiring publicly funded support and the majority of older people self-report good or excellent health (11). However, increasing demand for home care is expected with an ageing population with increasing prevalence of age-related disability and disease (10, 11).

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Supporting the preferences of many older people to live at home (rather than in residential care) aligns with Australian aged care policies that promote wellness and reablement (12), while respecting individual choices.

Essential elements of good quality health care for older people who need support to live at home have been proposed in other qualitative studies. These elements of good quality care have included the following: health providers being knowledgeable and skilled in geriatric care (13–15); holistic and person-centred approaches (16, 17) and effective communication skills (18–20). Several studies have reported challenges for care workers in promoting the self-determination of older people in home-based care decisions (21, 22). For example, despite wanting to do their best for older people, home care workers have reported struggling to fully involve older people in their own care due to time constraints (21). Effective relationships between home care providers and older people in delivering person-centred care (23) may be particularly important for older people with vulnerabilities such as cognitive and functional declines (21, 24).

The persistent nature of reported issues such as unmet needs (1, 2), limited responsiveness of care (5–7, 25) and poor communication skills (20, 26) suggests that gaps exist in knowledge about how to address well-known problems. In response to these gaps, our study was conducted to explore the quality of health care for older people who need support to live at home, from the perceptions of older people, carers and key informants.

Methods

The aim of our study was to investigate enduring issues older people face when interacting with healthcare services, to gain an in-depth understanding of what is involved in providing good quality health care for older people who need support to live at home. We selected a qualitative research paradigm (27) with an interpretive descriptive approach (28). Foundational underpinnings of interpretive description include an emphasis on: as naturalistic a context as possible; acknowledgement of socially constructed elements to human experience; and valuing of subjective and experiential knowledge (28). Our exploration was not framed with predetermined theoretical perspectives. However, the study design was guided by principles underpinning person-centred care of respecting the person's values, needs and preferences and respecting the person's right to self-determination (23).

Initial research questions explored how quality of health care for older people was experienced and perceived, and how quality of care might be improved. During our initial data analysis, two further research questions emerged, to explore how the role of the older person is placed in health care, and how the roles of the

older person in health care affect quality of healthcare delivery. We incorporated these questions into a secondary analysis of the qualitative data, in an iterative process which also incorporated further interrogation of the literature. A depiction of our interpretive descriptive approach is displayed in Figure 1.

Ethical considerations

The study was reviewed and approved by the University of South Australia's Human Research Ethics Committee (P200/08). To protect the privacy and confidentiality of third parties mentioned during interviews as well as participants, data were de-identified prior to member checks of initial findings and subsequent reports following further analysis. Pseudonyms were assigned to each participant.

Purposive sampling, recruitment and eligibility screening

Purposive sampling and recruitment sought participants who were likely to yield data that triangulated from diverse viewpoints (29) with the aim to achieve maximum variation in sampling (30). Three participant groups were selected:

- 1 Older people who needed support from informal carers and/or paid health and aged care services to live at home in the community, rather than in residential facilities.
- 2 Informal carers such as family members, friends or neighbours who provided regular care which assisted older people to live at home.
- 3 Key informants who had expert knowledge about community-based service provision for older people.

The first two sample informant groups (older people and informal carers) were selected for their lived experience. The third sample group were key informants, which have been described as 'individuals or groups with specific knowledge or expertise about the issue being investigated' (31). Hereafter, these three participant groups are referred to as *older people*, *carers* and *key informants*. Final numbers of participants were determined by theoretical saturation (29), and recruitment was ceased when new insights emerging during interviews tapered.

To recruit older person and carer participants, advertisements were placed in local newspapers, and recruitment flyers were distributed in local community centres and via a mobile library service for older people who experienced difficulties leaving their homes. Older people were invited to share their thoughts about quality of health care who were as follows: 65 years old or older, living at home, experiencing some difficulties with daily tasks and needing assistance from carers or providers. Carers were eligible for inclusion if they had supported older people who met the above inclusion criteria. Key

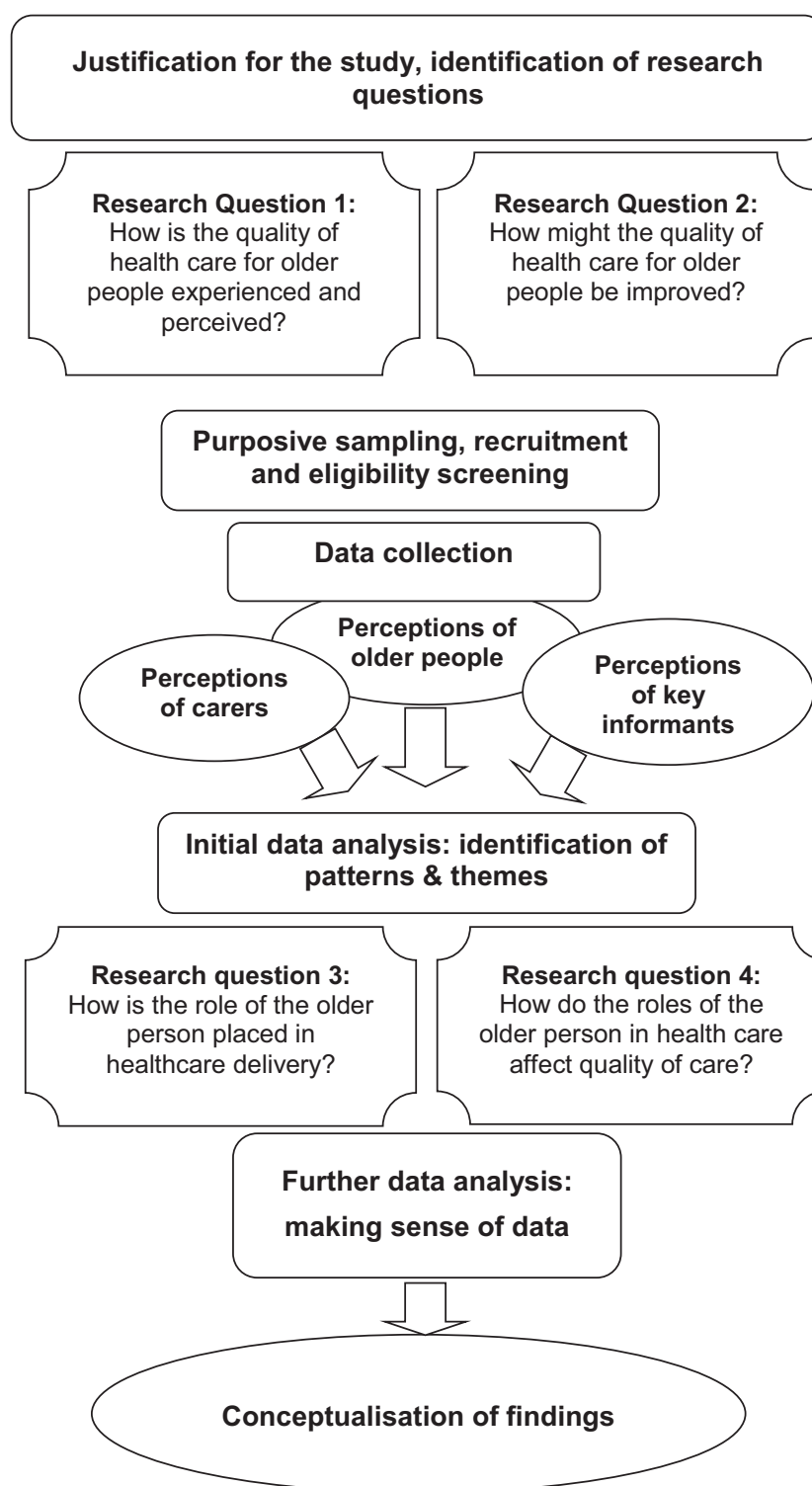


Figure 1 Research questions and interpretive descriptive approach.

informants were approached individually, and included people with extensive knowledge and leadership roles in the aged care sector, from government, health and non-government organisations.

Eligibility screening was conducted by the lead researcher (AG) by telephone. All of the older person and carer participants who expressed interest in participating in the study were eligible, and no dropouts occurred

Table 1 Purposive sample: Older people, carers and key informants

Older People (n = 7)					
Gender	Age Range (Mean age)	Living Alone	Medical Conditions	Functional Limitations	Supports and Services
Female (n = 5)	64 – 90 years (Mean age: 76 years old)	Yes (n = 6)	Acute and chronic conditions included the following: arthritis; cancer; cardiovascular disease; dermatitis; diabetes; respiratory conditions; stroke.	Activities of daily living (personal care, dressing, food preparation); Instrumental activities of daily living (cleaning, shopping); mobility; sensory impairments (hearing and vision).	Home support services (cleaning, equipment loans; personal care, shopping, transport); medical, nursing and allied health care; informal care provided by family and friends.
Male (n = 2)		No (n = 1)			
Carers (n = 8)					
Gender	Relationships to Care Recipients	Medical Conditions of Care Recipients	Functional Limitations		
Female (n = 8)	Daughter (n = 4)	Dementia; frail elderly; frequent falls; kidney disease; severe neurological conditions (stroke, Parkinsons Disease, Huntingtons Disease)	Activities of daily living (personal care, dressing, food preparation); cognitive impairment; Instrumental activities of daily living (cleaning, shopping); mobility; sensory impairments (hearing and vision); speech and swallowing disorders.		
Male (n = 0)	Spouse (n = 4)				
Key Informants (n = 11)					
Gender	Work Roles				
Female (n = 10)	Program director, Statewide aged care services; program team leaders, community aged care (n = 2); project officer, local government; Chief executive officer, Non-Government Organisation; quality assurance managers, Commonwealth programs (n = 2); quality assurance leader, Statewide aged care services; managers, integrated aged care services (n = 3).				
Male (n = 1)					

following screening. The purposive sample for older people, carers and key informants is summarised in Table 1.

Data collection

Semi-structured interviews were conducted with older people (n = 7), carers (n = 8) and key informants (n = 11). Interview guides customised for each participant group focused on exploring experiences of health care and thoughts about how quality of health care might be improved for older people who need support to live at home. During development of the interview guides, feedback from consumer representatives (six women, four men) led to slight simplifications of the guides. The interview guide for older people is displayed in Table 2.

In three pilot interviews, participants did not experience difficulties comprehending questions. Types of prompts that occurred during interviews were mostly prompts for elaboration, continuation or clarification (32) without interrupting conversational flow. Detailed information about the interview process was explained to participants, and informed consent was gained prior to interviews, including permission for interviews to be audio-recorded. Interviews ranged from one to two hours, with the average length being one hour and fifteen minutes. Interviews were transcribed verbatim by the researcher within several days of completing each interview. Additionally, analytic

Table 2 Interview question guide for older people

<i>Opening questions for older people who need support to live at home</i>	
1.	Tell me what you think <i>health care</i> is...
2.	What do you think is <i>good quality</i> health care?
3.	Have you had any experiences of good quality health care that you would like to share?[Prompt: What was it that was really good?]
4.	What is <i>poor quality</i> health care?
5.	Have you had any experiences of <i>poor quality</i> health care that you would like to share?[Prompt: What could have been done better?]
6.	What makes it tough for health workers to do their job well?
7.	Do you have any ideas about what could make health care better for older people?

field notes (28) were recorded by the researcher immediately following each interview to note reflective thoughts not captured by recordings.

Initial data analysis

A systematic approach was adopted for initial data analysis to code and categorise units of qualitative data to identify emergent patterns and themes (30, 33). These data were entered both in NVivo™ and Excel

Table 3 Themes from initial data analysis of interviews with older people, carers and key informants

Participant groups	Theme	Sub-themes	Examples of quotations from participants
Older people	Experiencing health care	Choosing to live at home.	I don't like those types of places [residential facilities] and I don't like being forced to chat and socialise.
		Strengths and vulnerabilities affecting experiences of health care.	I keep myself as active as possible. I do as much as I can.
		Essential elements in responsive health care.	I think people need to listen carefully to what the person is saying.
		Health care experienced as relationships.	He's a really caring doctor and he's easy to talk to.
Carers	Responding to needs	Experiencing the absence of care.	He was so abrupt. I was upset for three days.
		Being a carer.	You become very invisible when you are caring for someone with a disability.
		Working with health providers.	You have to work with them.
		Balancing the needs of carers and care recipients.	They have to look at you as being a person.
		Hitting the brick wall.	It becomes "This is the way it is going to be. So why bother."
Key informants	Placing the older person at the centre of care	Caring for the whole person.	It includes psycho-social, environmental and community networks. You need to look at the whole person.
		Characteristics of competent care.	Some people just don't have the expertise. Don't have the training. Not understanding the issues of ageing.
		Quality of care affected by 'the system.'	It should be a smooth system and it's not.
		Engagement of older people within health care.	Give older people a voice and listen to them and find out what they want to change and how they want to change it.

spreadsheets for coding, categorising and visual display of data by the lead researcher. Another researcher (experienced in qualitative analysis) reviewed interview transcripts, codes and categories. Member checks of initial analysis were sought from study participants. Twenty-five of the total twenty-six participants agreed to receive a written copy of initial findings, to check interpretive validity (34). Six people provided written comments and feedback, and two participants (one carer and one key informant) agreed to participate in follow-up interviews to discuss initial findings. No new topics arose during follow-up interviews. Themes from initial analysis are not fully reported here, due to this paper's emphasis on major findings from the completed study. However, an overview of themes from initial data collection and analysis is presented in Table 3. Major themes for each participant group were 'experiencing health care' (older people), 'responding to needs' (carers) and 'placing the older person at the centre of care' (key informants). Participants from all groups drew connections between communication skills, relationships between older people and health providers and quality of health care as perceived by older people.

Emergence of related research questions

Initial data analysis illuminated the influence of interactions and relationships between health providers and

older people on the experiences of health care for older people. However, the impact of these relationships and the roles of older people within healthcare systems were perhaps less well recognised as factors affecting quality of care than health provider-related factors of attitudes, knowledge and skills. To 'look beyond the self-evident' (28) in greater depth, further exploration was undertaken to explore emergent questions about the role of the older person in healthcare delivery, and how the older person's roles affect quality of health care. These emergent questions (Figure 1) were incorporated into secondary rounds of analysis.

Further data analysis: making sense of data

Iterative phases of further data analysis built on themes identified in the initial analysis. Major themes were finalised once all data had been gathered, visually displayed and reviewed several times over. Visual display methods (through use of colour coding and concept mapping) were particularly helpful during cross-comparison of data between the three participant groups. Also, the organisation and visual display of data (33) provided transparency in connections between the raw data, themes and major findings.

Further conceptual work extended the interpretive analysis beyond the self-evident. Additional searches of the literature were undertaken to test 'probable truths' (28)

derived from initial data analysis. Our literature searches sought evidence that would either validate, contradict or refute findings from perceptions of participants in this study. During this phase, we conducted a systematic review of the qualitative literature about perceived experiences of health care for older people to live at home (23).

Conceptualisation of findings

During the final phase of interpretive descriptive analysis, we closely considered distinctions between what is already known, and what meanings lay below the surface of apparent findings (28). We cross-compared themes from initial analysis (Table 3) with evidence from the literature, which included our systematic review of the qualitative literature about experiences of health care for older people who need support to live at home (23). We conceptualised findings derived from all phases of data collection and analysis.

Findings

Drawing together findings from all phases of the study, major themes emerged about meanings of partnerships in health care, and invisibility of the older person as a partner in health care. These themes address our secondary round research questions, which related to how the role of the older person is placed in healthcare delivery, and how the roles of the older person in health care affect quality of care. The metaphorical concept of 'invisibility' relates to the older person not being seen and heard as a *partner* in health care, as well as being a recipient of care. Our conceptualised findings of invisibility of the older person as a *partner* in health care are grounded in the meanings of partnership illuminated by our study, which drew on all data sources and phases of interpretive descriptive analysis.

Meanings of partnership in health care

Three elements of partnership in health care for older people who need support to live at home were illuminated by our study. Firstly, older people 'being treated as an equal' by health providers was understood to require being aware of the older person's sense of self, respecting the autonomy of the older person, and upholding their rights to be involved in decision-making about health care. Secondly, being involved in decision-making was found to be an essential element of partnership, necessitating mutual respect, communication and real opportunities for older people to participate in health care. Thirdly, making contributions which impact on health care and health systems demonstrated partnerships with older people engaged and involved in health care both inside and outside of the clinical encounter.

Being treated as an equal. Being treated on an equal basis was described by older person and carer participants as a valued aspect of their relationships with health providers. Older people felt treated as equals when their life history, knowledge and experience were noted and respected. They spoke about how conduct and communication of health providers affected their sense of being treated with respect as a person. Older people and carers were appreciative of the professional skills and knowledge of health providers and did not argue that all parties have the same levels of clinical knowledge. However, participants discerned when health providers were attuned to their strengths and vulnerabilities. Examples below demonstrated a lack of respect for the older person:

Being treated like they talk around you but not to you (Older person 1)

I think that some of them might think, well we're up here and you're down there and I like to be treated as an equal by the doctor. I'm the patient if I have any questions, whether they are for me or my mum, I want them answered. And I don't want to be treated like an ignoramus. I want to be kept informed. (Carer 1)

Failure to treat older people as equals was perceived to occur when health providers showed lack of awareness or willingness for older people to be involved as partners in planning, improvement and evaluation of healthcare services. Several carers and key informants made similar observations that older people who needed support to live at home were not yet placed on an equal footing with health providers in influencing the shape of healthcare delivery for older people. For example, one carer stated 'I like to be treated as an equal.' Many older people and carers talked about a need to 'be seen' as a person to establish respectful relationships with health providers. Key informants made similar observations about the importance of respecting and 'seeing' older people. A difference in emphasis between the groups was that older people and carers spoke mostly about being treated as an equal at an individual level in their relationships with health providers. Key informants made similar observations, but also spoke of giving 'voice' to older people to drive change in healthcare services. For example:

Give older people themselves a voice and listen to them and find out what they want to change and how they want to change it. Let them have an impact on change. (Key informant 1)

Being involved in decision-making. Older people's levels of involvement in decision-making were reported to vary, from perceptions of older people and carers. Older people perceived that their involvement in decision-making and control of health care depended on their own resources and preferences. Older people and carers alike viewed failure by health providers to assist older people to be

involved in health-care decision-making as a lack of respect for the older person. Several older people had adopted a 'doctor knows best' mindset at times, but expressions of desire for self-determination and to work with providers were also evident. These apparent fluctuations in older people's choices illuminated a varied nature of individual preferences with respect to desired levels of involvement in care decision-making.

Involvement in decision-making was perceived by participants from all groups to be an inherently relationship-based process. Older people and carers expressed that their own actions would have an effect on their relationships with providers, with consequent impacts on their experiences of care. For example, several older people described how they managed communication with health providers carefully to preserve good relationships. One carer stated simply 'You have to work with them'. Some older people and carers had avoided offending providers when they disagreed with or felt compelled to challenge a provider's advice. They understood that their involvement in decision-making in health care might not be well received by providers. Key informants recognised that communication and relationships between health providers, older people and carers affected the extent to which older people became involved in decision-making. Several key informants described barriers to older people's involvement. These barriers included lack of skill or awareness by health providers in deeply understanding older people's needs and issues. A barrier of paternalistic attitudes in health providers was illustrated by one key informant who said '...until people working with older people support the view that older people know best, and provide support to work that out, I don't think that anything is going to change.' When talking about enablers of good quality health care, one key informant drew connections between appropriateness of information and well-informed decision-making:

Good quality health care works in partnership with older people, so that the older person can actually have control. I mean, that the time is taken to really understand what is going on and people are given appropriate information, so people are informed for their decisions. (Key informant 2)

Making contributions which impact on health care and health systems. Contributions being made by older people and carers which were likely to impact on quality of health care were spoken of by participants from all groups (older people, carers and key informants). Types of contributions by older people as partners in health care included relationship-building with health providers, which was described by older people and carers. All carers provided example of activities assisting improvement of health services. However, it was unclear whether or not health providers had been fully aware of the extent of contribution

being made by older people and carers, or conscious of impact upon health systems. When talking about how they built good relationships with health providers, some older people showed empathy for rushed doctors, observing that doctors 'haven't got much time', as stated by one older person. The more explicit examples of contribution which were likely to impact on health care and systems were provided by carers in this study, not older people.

Every carer interviewed spoke of their own experiences of contributing to the improvement of health care. For example, through: preserving effective communication and relationships with health providers; conflict resolution between older people and providers; organising care for family, friends and neighbours; providing information to hospital- and community-based staff about the effects of neurological disorders (Parkinsons Disease, Huntingtons Disease, and Stroke); establishing support groups; and political advocacy to improve parking spaces and accessibility for older people with disabilities. Many of these accounts of contribution were likely to have achieved improvements in quality of health care. However, several carers described how acting as an advocate was at times an uncomfortable process. For example, once carer described how she had felt at one point:

They must think 'Thank God that daughter is not here!' But that is how you have to deal with the aged care system. You have to be this domineering daughter who says 'I want this, this and this' and that's the only way you can make sure it will happen. (Carer 2)

Several carers and key informants spoke of opportunities to solve problems and improve the quality of health care through increased involvement of older people in planning and service development. For example:

I would say that consumers themselves may be able to come up with solutions for problems and not just as a token gesture. (Key informant 3)

Invisibility of the older person as a partner in health care

The older person not seen as a partner in care. Our interpretive descriptive study found that the older person is not perceived as a partner in health care, if partnership is interpreted to mean being treated as an equal, being involved in decision-making and making contributions which impact on health care and systems. Invisibility of the older person as a partner in health care was evident from our reviews of the literature about older people's experiences of health care. We found sparse reporting from the literature reviewed about contributions by older people impacting on quality of health care.

During interviews with participants from all groups (older people, carers and key informants), the older person was predominantly viewed as a recipient of care and

not viewed to the same extent as a partner in health care. Thus, invisibility of the older person as a partner in health care manifested, including in the eyes of older people themselves. This was a common finding from all data sources for our study, including perceptions from all groups and our reviews of the literature. Several older people and all carers interviewed in our study had acted as partners in health care, as outlined in previous sections. However, low levels of recognition of older people as partners in health care were revealed in uncertainty about whether health providers had viewed older people as partners in care, or had considered the effects of these partnership roles on quality of health care.

The older person not placed at the centre of care as a partner in care. Not being placed at the centre of health care as partners in health care appeared to be symptomatic of low visibility of older people as partners as well as recipients of care. Poor experiences of health care were described by participants which indicated a lack of respect for the older person as a recipient of care. Several older people had encountered dismissive attitudes and inattention to needs by providers. Other examples were also provided of good quality care and good relationships with health providers. Erosion in quality of care was perceived to occur when health providers failed to acknowledge a role for the older person as a partner in care. Older people and carers spoke of tensions occurring when the older person lost control of their own care and were denied opportunities to be involved in decision-making. Older people described their loss of confidence:

No. I don't feel like I'm in charge of my care. (Older person 3)

I don't think a lot of people have a lot of faith in the system. (Older person 4)

Empowerment of the older person as a partner at the centre of health care was advocated by participants from all groups in our study. Older people shared their accounts of how they were involved in an everyday sense in managing their own care, and some wanted to help others by providing feedback to providers and by volunteering. Carers had all shared examples of their contributions (as previously described), and several carers were forthright in expressing a desire for improved levels of engagement between carers and health organisations. Several key informants advocated the merits of involving older people in government policy-setting, in addition to other forms of consumer engagement such as participation in advisory committees, support groups, advocacy and mentoring. In relation to older people being in control of their own care, one key informant made the following observation:

The older person doesn't want to 'be managed'. That's just our service language. The older person

wants to be empowered to manage their own health care. (Key informant 4)

Discussion

Our study found new insights centring on the roles of the older person in health care impacting on quality of health care for older people who need support to live at home. Major themes were around meanings of partnership for older people in health care, and invisibility of the older person as a partner in health care. We elicited three important elements of partnership in health care: being treated as an equal, being involved in decision-making and making contributions which impact on health care and health systems. These elements of partnership are consistent with principles of person-centred care, which entails respect for the person's values, needs and preferences, and respect for the person's self-determination (23).

Being listened to, seen and heard were experiences which affected the extent to which older people in our study felt treated as equals. Focus on sense of self and personhood has featured in other qualitative studies into experiences of health care for older people (18, 19, 35–37). Also, multiple forms of self have been described, including personality, social, cultural and familial aspects (38), all of which may be respected or violated by health providers interacting with older people. Respect for the person is influenced by values and beliefs in human dignity. Changing circumstances or vulnerabilities in the older person can lead to loss or violation of dignity. Thus, a challenge for health providers is to see the older person's sense of self and personhood, at all levels of functional and cognitive capacity. Respect for the autonomy of the older person has been reported in other studies (18, 24, 36, 37, 39) with emphasis on respecting the dignity and rights of the older person's self-determination of their own health care. A new insight from our study is that respect for the autonomy of the older person as a *partner* in health care is also fundamental. This requires the older person to be seen and heard as a partner in care, in addition to being seen and heard as a recipient of health care.

Being involved in decision-making emerged as an essential element of partnership between older people and health systems, but older people in our study reported varied preferences in their levels of involvement. Varied preferences were also reported from a case study of shared decision-making (40), which observed a continuum of involvement from paternalism (doctor makes the decision) to shared decision-making (decision made together) to informed choice (patient makes the decision). The authors concluded that older people value involvement in primary care, but to varying degrees, and cautioned that it is wrong for

providers to make assumptions about individual's preferences (40). Respecting the older person's choices infers a need for health providers to explore the older person's preferences about the extent to which they want to be involved in decision-making as partners in care.

In our study, participants perceived the involvement by older people and carers in decision-making about health care supporting older people to live at home to be an inherently relationship-based process. Similar findings have been reported from qualitative studies over the past decade which has highlighted the negotiated nature of engagement between older people, carers and health providers (41–43). Other studies have drawn connections between older people's perceptions of poor experiences of care and not being involved in decision-making (13, 37, 39). An implication arising from these findings is that greater involvement of older people in health-care decision-making may be dependent on the quality of relationships between older people and health providers. Furthermore, effective communication and good relationships enable exploration of the older person's preferred levels of involvement in decision-making, and adaptation to respect older people's varied preferences.

Examples described by carers in our study of advocacy and contribution by older people as partners in health care revealed impact upon health systems beyond shared decision-making inside the clinical encounter. Although there is growing evidence of patient involvement inside the clinical encounter (44, 45), the impact of partnerships beyond the clinical encounter (such as in planning, development and evaluation of health services) is less widely reported. There are shifts in policy and quality standards promoting greater involvement of consumers as partners in health care (46, 47), but strategies of implementation and evaluations are under evolved for older people as partners making contributions which impact on health care and health systems. To date, reporting of outcomes from partnerships between older people and health providers is limited. A notable exception is a series of studies conducted in Canada which investigated empowerment of older people in home-based care (48–51), with measurement of effects on health service utilisation. A guided conversation discussion guide was used with older people receiving home care, to elicit older people's choices about if, when and how they might be involved as care partners (51). Evaluation of use of their discussion guide to empower partnering approaches showed no significant differences in services consumed and associated costs. The self-reported surveys reported short-term improved outcomes in partnering experiences (measuring the older person's perceptions of involvement and overall experience of

partnering in home care) for older people using in-home services (51). Further investigations of this type would help us to better understand the effects of interventions which are designed to empower older people as partners in health care.

In relation to invisibility of the older person as a partner in health care, two sub-themes were revealed of the older person not being seen as a partner in health care, and not being placed at the centre of care as a partner in care. The dominance of an assumed role for the older person as a recipient of care (without similar levels of visibility of the role as a partner in care) pervades all aspects of healthcare delivery, including policy, service provision, quality frameworks and research. In our study, partnership in health care was presented as a deep level of engagement for the older person in health care. Lack of visibility of a role for the older person as a partner in care in the eyes of health providers, policymakers and researchers is likely to erode the autonomy of the older person as a partner in health care. Therefore, it is recommended that health providers respect the autonomy of the older person in multiple roles, including as a partner in health care, in addition to as a recipient of health care. This necessitates involvement of older people as partners in service planning, co-design, improvement and evaluation of health services, while accommodating the older person's preferences and choices.

Limitations of our study included several imbalances in purposive sampling across the three participant groups. Older person participants all met the inclusion criteria, but had higher levels of function than older people who had been cared for by the carer participants. Therefore, most of the insights which related to high levels of disability and cognitive impairments were sourced from carer perceptions. There was also gender imbalance, with only three of twenty-six participants being male. In sampling for key informants, diversity was achieved with experts from government and non-government agencies; however, we were unable to recruit any General Practitioners (GPs), despite multiple avenues being pursued.

Conclusion

The older person who needs support to live at home is not highly visible as a partner engaged in shaping healthcare delivery, to health providers, policymakers and researchers. The older person is more visible as a recipient of care, and is not yet placed at the centre of health care as a partner in care. Consequently, opportunities to address persistent issues with quality of health care may in future be achieved through stronger partnerships between older people and health providers, to find new ways to improve the quality of care for older people.

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Author contributions

Dr. Anna Gregory designed and implemented the study, with contributions from Dr. Shylie Mackintosh, Dr. Saravana Kumar and Prof. Carol Grech in the research, conceptual development and review of this paper.

Ethical approval

The study was approved by the University of South Australia's Human Research Ethics Committee (P200/08).

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