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Feature Article

Experiences of health care for older people who need support to live at home: A systematic review of the qualitative literature

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ABSTRACT

Perceived experiences of health care for older people who need support to live at home can illuminate areas needing improvement in quality of care, and guide towards better ways to support ageing populations to live at home. This systematic review synthesized findings from the qualitative literature about perceived experiences of health care for older people who need support to live at home, from the perceptions of older people, carers and health providers. Searches of electronic databases and eligibility screening produced 46 included studies for review. Thematic synthesis revealed how health care impacts on the older person's sense of autonomy, both in health care decisions and everyday life. Autonomy is empowered by the older person's own capacity and by respectful conduct of health providers. Engagement between older people, carers and health providers is a negotiated interaction, affected by multiple factors.

Introduction

Perceived experiences of health care by older people who need support to live at home are of interest to health providers for several reasons. Older people's perceived experiences may illuminate areas of practice for improvement in quality of care provision. Drive to continuously improve the quality of health care for older people is motivated by core values of respect for the rights and dignity of older people[1,2] and by increasing demand for care supporting older people to live at home.

Escalating demand for health care to support ageing populations to live at home is expected worldwide. Life expectancy continues to steadily increase, with the average life expectancy at birth (predicted in 2013) in OECD countries reaching 80.5 years.[3] The expectation of increasing demand for health care is due to increased prevalence of age-related disability and disease in ageing populations, which necessitate finding sustainable ways to support older people to live at home. Respect for the rights of older people is another important consideration. Rights of older people have been described as '… equality of opportunity and treatment in all aspects of life as they grow older'.[4] Goals to improve service efficiency can conflict with moral imperatives to meet complex needs of older people. This raises dilemmas for allocation of resources[5] that tend to be driven by focus on quantitative data. However, insights from the qualitative literature about perceived experiences of care for older people can assist policy-makers and health managers to navigate dilemmas, and to balance priorities in service planning to support older people to live at home.

Promotion of independence for older people who need support to live at home is grounded in a value of respect for the inherent worth and dignity of older people. Respect for the older person underpins person centered approaches to care for older people with long-term care needs.[6] Qualitative studies in community settings have reported findings of older people not feeling respected by home visiting care workers and health professionals, when the older person did not feel 'seen and heard'.[7,8] In hospital settings, lack of respect for older people with dementia has been observed, with dismissive comments by hospital ward staff,[9] and rushed encounters in Emergency Departments (ED) resulting in older people feeling ignored and forgotten.[10] Findings from these studies have revealed failures in appropriateness of care, and may inform future improvements to uphold a core value of respect for the older person.

Systematic reviews of the qualitative literature have raised concerns about experiences of health care for older people during times of transition and crisis, reporting stressful experiences of ED care[11] and loss of identity in acute hospital settings.[12] A common

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finding from systematic reviews of studies from hospital settings[11,12] and home-based social care[13] is that relationship centered aspects of care influence the perceived experiences of health care for older people. A systematic review of home-based social care[13] focused on care provision by personal care workers, and excluded health care. We found no reviews of experiences of health care for older people who need support to live at home, from differing perspectives.

To address this gap, we conducted a systematic review which addressed the question 'What are the perceived experiences of health care for older people who need support to live at home, from the perceptions of older people, carers and health providers?' We defined 'Older people who need support to live at home' as 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. 'Carers' were informal caregivers, who may be family members, friends or neighbors who support the older person to live at home. 'Health care' spanned health and aged care provided by clinicians and non-clinical workforce. 'Health providers' were clinicians and non-clinical workers.

Objective

The objective of this systematic review was to synthesize the qualitative literature about perceived experiences of health care for older people who need support to live at home, from the perceptions of older people, carers and health providers.

Methods

Search strategies

Searches were conducted on electronic databases: Ebsco Host (Ageline, CINAHL, and Psychology and Behavioral Sciences Collection) and Ovid (Embase, Medline and PsycINFO). Key words were: older person, home care services, perceptions and qualitative studies. Searches were expanded with use of truncation symbols, and through expansion of subject headings for key words. Publication language was limited to English, due to pragmatic constraints of limited resources for translations. Publication dates were limited to a range from 1995 to November 2015, to maximize the relevance of findings to contemporary practice and research. This time period (since 1995) captured the expansion of home-based support services for older people, and more recent shifts towards consumer directed care. Initial searches identified a large number of relevant qualitative studies published in peer reviewed journals. Broad searches including grey literature were undertaken in the formative stages of the review; however, comprehensive searching of the grey literature was not undertaken due to limitations of search engines. Reference lists of included studies were scanned to identify potentially relevant articles from websites and peer reviewed journals. The search strategy used for Ebsco Host databases is presented in Table 1.

Table 1
Search strategy for Ebsco Host databases.

Key words and terms	Limitations
('older person' OR 'older people' OR elder*) AND (perception OR view* OR perspective) AND ('community care' OR 'home care' OR 'domiciliary care' OR 'social care' OR 'aged care') AND qualitative OR ('older person' OR 'older people' OR elder*) AND (perception OR view* OR perspective) AND (caregiver OR carer) AND qualitative	Publication dates from January 1995 to November 2015. Limited to English

Eligibility criteria

Qualitative studies and mixed methods studies with qualitative data collection and analysis were included. Systematic reviews, quantitative studies, methodology or diagnostic tool studies and opinion articles were excluded. Participants included: older people (aged 60 years or older) who needed support to live at home; carers; and health providers. Younger people, carers and health providers who provided care for young disabled people and older people not needing support to live at home were excluded. The phenomena of interest were perceived experiences of health care for older people who need support to live at home. Studies of palliative care, end of life care and advanced care planning were excluded. The context was community-based settings, not residential facilities. Hospital-based studies were excluded if they reported about acute care only, with no relevance to care supporting older people to live at home.

Study screening

Titles and abstracts of potentially relevant citations were independently screened by two reviewers (AG and SM). Where relevant abstracts lacked sufficient detail to determine eligibility, full text reports were retrieved. Any discrepancies in eligibility screening of titles, abstracts and full text articles were resolved through discussion. Reasons for exclusion of full text articles retrieved were recorded.

Critical appraisal

The critical appraisal skills checklist program (CASP) checklist for qualitative studies[14] was used by two reviewers who assessed the quality of studies. The CASP checklist has been used in other systematic reviews of qualitative literature published in peer reviewed journals about care of older people[15–17] and the criteria to assess congruity and credibility of findings are similar in content to other appraisal tools.[18] The first reviewer (AG) critically appraised all included studies. Another reviewer (SK) independently appraised a select sample of five studies as a means of establishing reliability between the reviewers. Any discrepancy in the critical appraisal process was resolved by an independent third reviewer. Three criteria (clear statement of aims; qualitative methodology appropriate; and data analysis sufficiently rigorous) were regarded by our review team as mandatory criteria for inclusion of studies.

Data extraction

Data were extracted and recorded on customized data sheets by the first reviewer (AG). Data items included: authors and date of publication; context (country and setting); methodology or research approach; purpose/aims; participants; recruitment strategies and sampling; methods of data collection and analysis; and key findings.

Data analysis and synthesis

Data analysis incorporated thematic synthesis, similar in approach as reported by Thomas and Harden.[19] Their approach to thematic synthesis involved three stages: coding of text 'line-by-line', development of 'descriptive themes', and generation of 'analytic themes'.[19] For our systematic review, themes were developed by coding and categorizing all extracted findings, followed by