Client Perceptions of Quality Care in Aged Care Services

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Quality Jobs = Quality Care

contents

introduction

Over one million older Australians currently receive aged care services, and these services are expected to come under increasing pressure due to the ageing of the Australian population, growing expectations of the nature of services, and the ageing of the aged care workforce (Productivity Commission, 2011). While much attention has rightly been paid to the macro-level of service delivery given its importance in ensuring the sustainability of care, less focus has been placed on the quality of care, as experienced by care recipients. The *Quality Care and Quality Jobs: Improving work practices to deliver quality aged care jobs and aged care services for older Australians* project highlights the importance of quality in the nexus between service delivery and design of jobs in the aged care sector. Research has shown that improvements in job design are associated with improvements in business performance and the quality of service (e.g. Adams & Sharp, 2013; Bailyn, 2011; Bailyn & Fletcher, 2002, 2007; Banerjee, Daly, Armstrong, P., Szebehely, Armstrong, H. & Lafrance, 2012; Charlesworth & Baird, 2007; Rosati, Marren, Davin & Morgan, 2009). Accordingly, this project focuses on the integrated nature of quality – from the perspectives of the care recipients and the workers providing the service.

The purpose of this literature review is to stimulate discussion on how quality from the care recipients' perspective can be meaningfully evaluated, and in doing so, form the basis for developing benchmarks and interventions designed to improve the experience of receiving care. This review targets contemporary literature examining quality from the viewpoint of older Australians who receive aged care services in the residential and community sectors. It addresses current and emerging issues in the literature, predominately from studies published from 2010 onwards. The review emphasises Australian research on quality in aged care but also draws on what can be learned from international initiatives that have been evaluated in the literature.

Evaluating quality of care

Quality of care is a subjective experience and much of the research that examines the meaning ascribed to quality has been derived using qualitative research, primarily semi-structured interviews (e.g. Bourgeault, Atanackovic, Rashid & Parpia, 2010; Bradshaw, Playford & Riazi, 2012), and less frequently focus groups (Turjamaa, Hartikainen & Pietilae, 2013) and surveys (e.g. Eloranta, Arve, Isoaho, Welch, Viitanen & Routasalo, 2010). Researchers recognise the limitations of surveys in studying the experience of older subjects, who may have sensory, attentional or neurological impairments which limit their ability to fully participate (Rodriguez-Martin, Martinez-Andres, Cervera-Monteagudo, Notario-Pacheco & Martinez-Vizcaino, 2013). In addition, the construction of surveys can constrain the nature and depth of the issues explored, and so surveys are less likely to extract the subtlety of meaning that participants attribute to specific issues.

Conversely, client satisfaction, a concept related to perceptions of quality of care is frequently evaluated using surveys (e.g. Rosati et al., 2009). Surveys may be useful when the target audience is motivated and physically and cognitively able to complete them. As a result surveys have been used more frequently to evaluate care in low care services. The recent literature has shown a trend away from measuring client satisfaction, as was popular in the early 2000s (e.g. Boldy, Chou & Lee, 2004; Robinson, Lucas, Castle, Lowe & Crystal, 2004). Client satisfaction is generally examined as more global perceptions of the adequacy of services associated with care. In fact there is dispute in the literature as to the value of measuring client satisfaction since the concept lacks a theoretical basis and standardisation. There remains no consensus on how best to conceptualise the relationship between client satisfaction and client perceptions (Gill, White & Cameron, 2010). In addition to exploring satisfaction with broad parameters of care, like the quality of inter-personal and service interactions, such surveys typically include client ratings on the amenities, catering, and social activities (e.g. Wright, Capra & Connelly, 2010). Since the literature on client satisfaction takes a more global but superficial view of the quality of care, its relevance to perceptions of quality is questionable; and as the studies are not current, it is therefore not included in this review.

Emerging in the recent literature, another method for evaluating the quality of care from the care recipient perspective is the systematic review. Literature reviews accumulate learning by reviewing multiple sources of information. Doing so avoids the risks of relying on single studies. In addition, systematic reviews apply explicit methods to the literature review process, based on extensive searching and assessment of the rigour of studies (Harden, Garcia, Oliver, Rees, Shepherd, et al., 2004). A systematic review typically defines the parameters of the research participants, methods and sample size to determine the robustness of the research, and then collates the findings. In relation to the quality of care, several recent systematic reviews have been published. Most of these reviews focus on the relationship between the quality of care and the quality of the job (Chenoweth, Jeon, Merlyn & Brodaty, 2010; Pol-Grevelink, Jukema & Smits, 2012; You, Dunt, Doyle & Hsueh, 2012). However, Bradshaw and colleagues (2012) and Low and colleagues (2011) conducted systematic reviews that addressed the quality of care focused on the experiences of care recipients, and these results are discussed further under the significant themes described later in this review.

Quality matters but what does it mean?

Quality can be conceived of in many ways by different audiences based on their experiences, motivations and roles. Common meanings of quality embrace notions like effectiveness, efficiency, safety, comfort and dignity (Oosterveld-Vlug, Pasman, Gennip, Muller, Willems et al., 2014; Productivity Commission, 2011). Quality of care is a social construct that takes different forms influenced by age, gender, social circumstances and state of health (Rodriguez-Martin et al., 2013). Quality is therefore multi-dimensional and is highly personalised in how it is experienced. The Productivity Commission (2011) proposes three primary and complementary approaches to ensuring the quality of care. These approaches include standard setting and monitoring, promoting commitment to quality improvement, and increasing competition and the information provided to care recipients. Although these policy initiatives provide a framework for improvement in care, they do not explicate how and what constitutes the quality in care that is sought by recipients. Neither do these approaches assist service providers to identify specific initiatives that enhance quality of care commensurate with quality of life (O'Dwyer, 2013).

The literature addresses quality of care in the following ways: First, care is characterised by the dimensions of service delivery relating to the care itself. Important dimensions include that the care is readily accessible; available when, and for as long as needed; reliable; and delivered in a respectful manner that supports independence and autonomy (e.g. Dow, Sparrow, Moore, Gaffy & Yates, 2013). Second, quality can be seen to include resident satisfaction with the structures governing the care and the amenities provided. Important factors here include having policies, procedures and systems that are easy to understand (Dow, Sparrow et al., 2013); access to personal space, freedom from noise and intrusive distractions (Adams & Sharp, 2013); use of personal possessions; and access to outdoor space (Chin & Quine, 2012; Dow, Sparrow et al., 2013). Third, quality is considered to be an outcome of the process of care and can be objectively measured in terms of clinical indicators, such as falls, infection rates and medication management (Alzheimer's Australia, 2013; Courtney, O'Reilly, Edwards & Hassall, 2009; Courtney, O'Reilly, Edwards & Hassall 2010; Meyer, Dow, Bilney, Moore, Bingham et al., 2012; O'Reilly, Courtney & Edwards, 2007).

Notwithstanding the range of perspectives relevant to examining the quality of care, most of the literature that addresses the recipients' perspective focuses on the concept of quality as arising from the care process itself. Given that the relationship between the quality of work and the quality of the care itself is the focus of this project, features of the care process and their meaning to care recipients are now explored in greater depth. The review begins with an analysis of studies relating to interpretations of quality by residents in the residential sector, followed by perspectives of clients using community, home and transitional care services. Studies that have been conducted within Australia are discussed first, followed by relevant examples from the international literature. The main themes are then summarised to identify the salient features of quality care from the recipients' experience. The review concludes with a summary that highlights possible linkages to improvements in the care process.

Quality in the care process

Perspectives of clients in residential care

Theme 1 – Positive interpersonal relationships

There has been recent research activity in Australia examining the quality of care in the residential aged care sector. Four highly relevant studies were identified that emphasise the importance of positive interpersonal relationships within care provision and social relationships within the facility. Adams and Sharp (2013) reported two qualitative studies in Australian residential aged care that identified reciprocity as fundamental to the quality of care. Positive reciprocity promotes the provision of care where both the care recipient and the care worker benefit directly from the relationship (Adams & Sharp, 2013). Reciprocity, by its nature, has instrumental and communicative dimensions. The communicative aspect produces the recipient's sense of being cared for by the care worker. Central to the idea of reciprocity is that the care recipients are valued as individuals and that both care giver and recipient participate in an on-going partnership where the care work is a function of day-to-day attention and accomplishment. In this process, the care recipient contributes to the decisions about their care, creating a sense of independence and control.

Theme 2 – Autonomy, control and decision-making

In exploring the autonomy and decision-making of residents in Australian residential aged care, Ibrahim and Davis (2013) highlighted that residents were constrained in making informed choices due to care workers' fears of residents being harmed. Gaining dignity through the experience of accepting calculated risks is encompassed in the term 'dignity of risk'. In practice, 'dignity of risk' is an expression of autonomy, a basic human right; and acknowledges that the ability to accept risks may be associated with short-term increases in quality of life. Impediments to residents being able to exercise their autonomy and to take risks arise primarily from their fluctuating ability to make informed decisions, given cognitive impairments. In addition, several factors related to care workers acted to constrain residents' choice. These factors included the involvement of multiple decision makers in the residential setting; inconsistencies between their espoused values and actions, due to risk aversion; and confusion and fear regarding legal responsibilities and duty of care. Possible solutions may be found through supporting residents in their decision-making, adopting a shared vision between the multiple decision makers, resolving disparities between actions and values; and establishing clarity of roles and legal responsibilities for care providers.

Autonomy, decision-making, dignity and risk are at the forefront of residents' concerns about the quality of care at the end of life. Interestingly, specific concerns about the quality of palliative care did not emerge explicitly in studies examining the global concept of quality of care, with the exception of an Australian study by Dow and colleagues (2013). This study reported on a review of 59 consumer

responses to the Productivity Commission Inquiry into Caring for Older Australians (Productivity Commission, 2011). The majority of participants were passionately vocal in demanding greater control and choice over the process of dying and death, including client-centred palliative care (Mitchell, Nicholson, McDonald & Bucetti, 2011). Alzheimer's Australia (2013) also highlighted care recipients' concerns about the quality of end of life care in their recent report on the quality of care in residential aged care services. This report cites data from the Australian Institute of Health and Welfare that shows only 22% of permanent aged care residents who died in 2010-2011 received palliative care services. This is concerning given that around 70% of residents dying each year are estimated to be likely to benefit from palliative care services (Alzheimer's Australia, 2013 p. 13). Inadequate staffing and care workers' time are significant barriers to the capacity to deliver quality palliative care, where care is tailored to clients' needs (Mitchell et al., 2011). Other issues that highlighted the centrality of decision-making autonomy and control to clients' perceptions of quality care during dying and death included voluntary euthanasia, advance care directives and choice of place of death (Dow, Meyer, Moore & Hill, 2013).

Elaborating further on the theme of autonomy and choice, the Alzheimer's Australia (2013) report emphasised the frequent use of chemical and physical restraints, particularly for residents with dementia, as a threat to residents' rights. Physical restraints such as harnesses, and chemical restraints, such as anti-psychotic medications, are used to manage high levels of agitation, restlessness, wandering and aggression. Current debates suggest that more emphasis is needed on behavioural interventions as a first line of treatment, supplemented with protocols that carefully control the prescription of these medications for situations where 'aggression, agitation or psychotic symptoms of dementia cause severe distress or immediate risk of harm' (Alzheimer's Australia, 2013 p. 9).

In another Australian case study using in-depth qualitative methods, De Bellis (2010) evaluated the quality of care of three highly dependent residents in an accredited residential facility. This study revealed markers of the absence of quality care, which at the extremes can point to neglect. Consistent with other studies that have examined quality from a positive viewpoint, aspects of care most evident in the work of De Bellis (2010) were care workers not having sufficient time, skill or empathic attitudes toward providing suitable care; poor quality technical care practices; the need for care activities to be supported by accurate documentation; creation of an appropriately stimulating environment; and resident autonomy and advocacy.

Theme 3 – Independence

Related to the theme *autonomy, control and decision-making* is the third theme, independence. In an interview study, the experiences of 11 older women living in their homes were compared with those of 25 older women living in Australian aged care facilities. Chin and Quine (2012) found that the concerns for the future held by the women living at home became the realities of those living in residential care. Moving into a residential care facility usually occurs when older people are

vulnerable and have exhausted most other options for independent living. For many of the participants in this qualitative study, the transition was frequently marked with a sense of great loss and despair. Women living in their own homes feared that living in residential care would result in them losing their independence, control over their lives, privacy, ability to make choices, and being forced to adapt and accept their situation. Residents in care facilities spoke of their loss of privacy and friendships, and their limited ability to take active control over their lives, such as to 'please yourself', rather than 'fit in with routines' (Chin & Quine, 2012 p. 273). Important in residents' sense of loss and the desire to 'be at home' was access to outdoor space, light, air and nature. Also important as part of the sense of control and the feeling of mastery was the notion of 'a sense of sameness' where residents could have knowledge and security in knowing that their personal space would be just as they left it when they returned (Chin & Quine, 2012 p. 275). An example offered by several residents was that they could not choose with whom they sat to have their meals. This study revealed that residents had strategies for identifying and creating choices to adapt to their new living arrangements. Salient in the findings was the importance of good facility design to enhance opportunities for activities that promote pleasure and social interactions, such as safe access to garden spaces, nooks for quiet reading, thinking or conversation (Chin & Quine, 2012).

Theme 4 – Positive stimulation and enjoyment

Quality of life and care in aged care is also related to positive stimulation and enjoyment. Thomas and colleagues (2013) studied the importance of leisure activities to a sample of Australian aged care residents in terms of their quality of life and satisfaction with care (Thomas, O'Connell & Gaskin, 2013). Leisure activities were seen as a significant means of social interaction, being able to form friendships, and avoid feelings of isolation and boredom. Maintaining close contact with family members was also seen as integral to ensuring a sense of social connectedness, whether this occurred through personal visits, phone calls or other modes of communication technology. The opportunity to participate in private activities was also important in providing solace, time for reflection, and achieving a sense of calm. Outings beyond the aged care facility also presented valued opportunities for connecting with the outside world, as did reading newspapers and listening to the radio. In addition to leisure activities, visits to the hairdresser and manicurist also provided social interaction, time for relaxation, the continued sense of pride in personal appearance, and an enjoyable experience of pampering. These activities are consistent with fulfilling the human need for contact, general acceptance and rapport (Adams & Sharp, 2013).

International studies

Beyond Australia, recent studies in residential aged care were identified in Spain, Norway, the Netherlands and United Kingdom. Residents of a nursing home in a Spanish study participated in in- depth interviews designed to explore what quality of care meant for residents (Rodriguez-Martin et al., 2013). The study involved 20 participants with no cognitive impairment and eight people who could provide proxy information on behalf of a sample of residents with cognitive impairment. Thematic analysis revealed that participants viewed quality of care in two distinct ways. Like Adams & Sharp (2013) who identified instrumental and communicative dimensions of reciprocity, the Spanish study identified that quality was first, inherent in features of the care that related to the persons providing the care, and second, as institutional aspects of care (Rodriguez-Martin et al., 2013). In their discussions, residents focused more on the aspects related to persons delivering care than institutional factors. Care-providers were seen to be central to creating quality through their application of emotional and technical competencies, where emotional competencies were seen as the vehicle for delivering technical competencies.

Consistent with the theme *positive interpersonal relationships*, a Scandinavian study also emphasises the importance of interpersonal aspects of care in care giver-client interactions (Nakrem, Vinsnes, & Seim, 2011). The important aspects of interpersonal care revealed in that study were physical care, protecting the clients' integrity, self-determination and independence, and psychosocial well-being. In a Canadian study, residential care was examined as an example of equity in practice, expressed as respect for bodily integrity and personhood, equality in access to services, and the right to respect for cultural differences (Armstrong, Armstrong, & Daly, 2012). An example from that study that illustrates inequity is the use of incontinence aids in preference to toileting and attention to activities of daily living. Care workers interviewed in this study reported that policy forbade incontinence aids be changed unless saturated, yet the costs incurred from using aids meant that they were rationed. This policy and practice led to indignity for residents and guilt and dissatisfaction for care workers (Armstrong et al., 2012). The authors suggested other indicators of the quality of resident care may be the use of drugs in pain and behaviour management, and staffing levels.

Theme 5 - Individuality

Enhancing residents' individuality and independence is a consistent theme in the literature. Promoting the use of personal resources by cognitively intact aged care residents has also been associated with increasing well-being, meaning in life, hope, spirituality and self-transcendence (Haugan, 2014; Haugan, Hanssen, & Moksnes, 2013). These two Norwegian survey studies showed that engagement in meaningful life activities is crucial given that transition into care is frequently associated with feelings of loss in function and social opportunities, leading to increasing loneliness and depression (Haugan, 2014; Haugan et al., 2013). Interpersonal transcendence included aspects such as having interests, being involved, sharing wisdom and finding meaning in spiritual and

cultural beliefs (c.f. Bourgeault et al., 2010). These studies suggest that enhancing the ways for care-givers to interact and communicate with nursing home residents may have a positive influence on residents' sense of hope, purpose and spirituality, which have been shown to be closely connected with individuals' quality of life, health and well-being (Haugan, 2014; Haugan et al., 2013).

Adding to the evidence on the relationship between individuality, independence and well-being, an interview-based Dutch study examined 30 recently admitted nursing home residents' experiences of dignity, and the factors that influence it (Oosterveld-Vlug et al., 2014). Ill health, the loss of independence and the threat to individuality were significant factors found to undermine personal dignity. However, living in a nursing home, of itself, was not seen as the cause of feelings of low worth. Instead, functional impairment and loss of capacity eroded dignity. Aspects of care related to lower feelings of dignity were residents' need to constantly wait for care, perceptions of powerlessness and the sense of being dictated to by care workers, and not receiving sufficient attention. In contrast, high standards of empathy and respect in the delivery of care, and the provision of a supportive social environment were highly associated with positive experiences of dignity (Oosterveld-Vlug et al., 2014).

Consistent with the findings of the foregoing Australian studies, the fundamental desire for residents' individuality and independence and how to effectively support these was echoed in a UK case study. These researchers immersed themselves in the care environment to observe and interview participants in one residential aged care facility (Stone, Brownlie, & Hewer, 2011). Their case study aimed to provide a rich description of the experience of being a care recipient, reflecting heavily on the desire for independence and the role of the care worker in fostering that independence. Issues that arose for the resident were the regimented nature of institutional rules and the threat to independence in the face of diminishing physical capacity. Residents adopted strategies to minimise threats to their autonomy and control, and to maximise and maintain their independence by expressing their wishes verbally as well as physically through mobilising, using wheelchairs and mobility aids. Residents' tensions with the care process and its perceived erosion of independence have implications for those residents unable to express themselves due to cognitive or physical impairments. The increasing dependence, frailty and disability in the older aged care residents now entering facilities makes quality of care a pressing, yet difficult to meet need given the demands on the aged care system.

Findings on residential care from systematic reviews

As previously discussed, systematic reviews integrate multiple sources of collated data to produce aggregated evidence. The systematic review of Bradshaw and colleagues (2012) in the UK examined quality of life and care in residential care homes. Supporting the findings of other recent studies, this review identified the following themes: residents' acceptance and adaptation to the living arrangement, connectedness with others, the importance of a home-like environment, and the practices involved in providing care (Bradshaw et al., 2012). In residential care, the lack of privacy and dignity, rigid routines, and loneliness and dependence can negatively affect a person's sense of autonomy and control (Bradshaw et al., 2012). Residents expressed concerns about their lack of autonomy and difficulty forming appropriate social connections. How care is provided is at the heart of residents' experiences in the residential care setting. Residents emphasised their necessity to feel that their needs were important to care workers and were being adequately met, and in particular that sufficient time was being provided to fulfil those needs 'before rushing off to complete the next task' (Bradshaw et al., 2012 p. 435). Dow and colleagues (2013 p. 238) referred to this form of interaction as having 'face time'. The inability to spend adequate time can leave residents feeling lonely, vulnerable and marginalised. Inadequate time to care often arises from short staffing where workload increases and care work becomes intensified (Armstrong et al., 2012; Banerjee et al., 2012). Care workers' caring attitude was also seen as crucial to positive care experiences. The care workers' ability to know their residents, their personal needs and life stories also contributed significantly to being able to deliver individualised care that recognised the humanity and dignity of the care recipient (Bradshaw et al., 2012).

Caring competencies in the residential sector

In the residential sector, quality of care was seen to be underpinned by the competency of the care workers in providing the care. Residents placed much emphasis on emotional competencies, including goodwill, kindness, warmth, empathy, patience, cheerfulness, and a sense of humour as being core attributes of proficient care staff. Technical competencies were also crucial to residents' health and welfare but were secondary to the way in which the care was delivered. At the heart of technical competence was the ability of the care worker to provide individualised care as part of a therapeutic relationship. Quality of care also embraced technical standards for health care, with many residents reporting the peace of mind they had in knowing that professional help and support were available when needed (Nakrem, Vinsnes, Harkless, Paulsen & Seim, 2012; Rodriguez-Martin et al., 2013). With regard to nursing homes' services, residents saw quality in care as meeting residents' needs and paying attention to individual details, such as knowing the individual residents' likes and dislikes, and providing time to develop relationships. Residents also valued their independence and autonomy and preserving these was an important combination of applying emotional and technical competencies (Rodriguez-Martin et al., 2013).

Perspectives of home, community and transitional care clients

Four recent Australian studies examining client perspectives of quality in community, home or transitional aged care were identified. Since community-based clients are less likely to have high care needs and be less restricted by cognitive deficits, studies in this sector are more likely to adopt survey methods than studies conducted in residential care. Three studies adopted the use of questionnaires to gain insight into the opinions of community care recipients. International research included two studies, one survey study completed in Finland and the other a qualitative interview study in Canada, and an Inquiry conducted in the United Kingdom.

Transitional care

Transitional care aims to support the independence of older persons with ill health as they move between home care, hospital care and residential care. The co-ordination and tailoring of services to need is the cornerstone of successful intervention in this mode of service delivery. To examine expectations of transitional care in Australia, a survey has been designed that seeks to reveal the determinants of client perspectives of quality (Gill et al., 2010). The survey assesses three broad dimensions of quality: the interpersonal, technical and administrative, with subdivisions addressing the nature of interactions, relationships, outcomes, expertise, timeliness, operations and support related to transitional aged care. This research identifies the essential aspects of quality from the care recipients' perspective as service co-ordination, integration and continuity; provider-client communication and interaction; client independence, health, safety and not feeling alone; social facilitation; and the availability of suitable aids and equipment (Gill et al., 2010).

Another Australian study examined the expectations of 55 elderly clients' prior to receiving community care services (Harrison, Low, Barnett, Gresham, & Brodaty, 2014). The method involved a research nurse first undertaking a comprehensive assessment of client needs during an interview. Clients' own perceptions of needs were then assessed using a questionnaire to determine the number of needs that would, or would not be met by the available community care services. The results showed differences in how needs were perceived by clients and professionals. Client expectations of the services they would receive did not correspond with the needs they identified as currently unmet while living in their home environment, with the exception of domestic support and personal care. Clients had expectations that services would address needs for socialisation, nutrition and monitoring of health and medication that would enable them to retain a level of independence.

A recent Australian study by Renshaw and Fine (2013) examines the possibilities for measuring outcomes in case managed community care. While this study sourced qualitative data from case managers rather than care recipients, the findings were consistent with other studies of community care. Respondents reported that clients valued the ability to remain safe and supported at home, independence and 'having a life' that involved community contact, family connection, having health

needs addressed and having care workers matched to the clients' needs. Case managers recognised the importance of being familiar with each client as an individual with a history, communicating effectively and adopting a 'person-centred' approach.

Teicke and Sitek (2013) evaluated community care services delivered by an Australian care provider. The results revealed that clients were less satisfied with all elements of their lives, were more lonely and socially isolated (cf Pate, 2014), reported poorer self-assessed health, and demonstrated higher levels of psychological distress and anxiety/mood disorders than a comparable sample of older Australians. Care recipients also commonly reported low levels of personal autonomy and control over their lives. The care recipients in this study commonly described a happy life as one that involved connection, good relationships, and participating in social activities. To achieve these outcomes, they hoped for connection and companionship from the services they received.

International research on community-based care

In terms of international research, a recent study from Finland (Eloranta et al., 2010) and an older study from Canada (Aronson, 2002) specifically addressed clients' experiences of quality in community aged care. In a survey study of 200 Finnish home care clients, their perceptions of psychological well-being and care were compared with a group consisting of 370 of their care workers (Eloranta et al., 2010). The findings highlighted important divergences in opinion about the nature of care. Care workers believed that their clients felt more depressed than the clients themselves reported. The care workers also perceived that their clients suffered from loneliness significantly more than the client group themselves reported. The client group was also more critical of the care they received in that it did not sufficiently encourage independence. In particular, recipients were dissatisfied with the quality of the physical care (dental, vision and hearing care), psychological care (support for managing depression and loneliness) and the social care received (motivating relatives to participate) (Eloranta et al., 2010). Clients in this study were most critical in regard to care workers' efforts at motivating clients toward independence, with significant differences between client and care worker perceptions. Clients reported that the care workers did not take adequate account of the clients' abilities and resources or their capacity to make appropriate use of those attributes, which contribute to clients' feelings of safety while living at home.

Theme 6 – Feelings of safety, security and control

Feelings of safety, security and control in one's own home are consistent themes in the literature on home-based care, as reflected in the Canadian study by Aronson (2002). Twenty women receiving home care support were interviewed twice a year over three years about how their lives were changing and the impact on their quality of life (Aronson, 2002). Clients' perceptions of their quality of care were associated with 'taking charge' of the care (Aronson, 2002 p. 404). In practice this involved making active efforts to control their situations and the conditions under which care

workers could enter their homes and become engaged in the private aspects of their lives. Clients spoke of making the care arrangement 'work for me' (Aronson, 2002 p. 404) by negotiating aspects of care, such as seeking to minimise bodily exposure but setting up conditions for safety, such as leaving the bathroom door open when showering.

Inevitably when capacities declined and dependence increased, home care clients reported themselves to be 'living on the edge', emphasising their sense of diminishing control (Aronson, 2002 p. 407). This lack of control manifested in emotional and practical ways in terms of being unable to manage their external environments, or mask their associated despair. Many clients expressed the need for consistency in the providers of their care support. Feelings of lack of control were heightened by being a stranger to the care-provider. Having to adapt to frequent new care providers led to clients feeling unknown, disrespected and trivialised. Home care recipients were also distressed by the timing of services where they found care workers bound by the clock rather than focused on the client's immediate needs. Tensions about time resulted in the care workers' experience of being rushed and stressed transferring to care recipients. In coming to terms with their changing needs, recipients realised that care would not adapt to them and their wishes, but rather they would need to adapt to it, gradually allowing their interaction with the wider world to shrink and their independence and autonomy to erode.

In the United Kingdom, the Close to Home Inquiry into Older People and Human Rights in Home Care (Equality and Human Rights Commission, 2011) received submissions from and conducted focus groups with older people and their family members. Findings revealed the significant issues for care recipients to be the lack of autonomy and choice, inflexibility of services, lack of respect for privacy, lack of personal security and insufficient attention to diverse needs. Consistent with the studies reported here, this inquiry also highlighted older persons' desire for social and civic participation and the ability to maintain family relationships as being at the heart of quality community care.

Findings on community care from systematic reviews

Two systematic reviews, both undertaken by Australian researchers examined client satisfaction with different models of home and community care. In the first of those systematic reviews, three models of care delivery were evaluated (Low et al., 2011). Case management is designed to deliver benefits for consumers through improvements in clinical and health outcomes, while integrated care concentrates on the efficiency of the care system. Consumer-directed care, the focus of current care delivery policy, allows clients and their care-givers to make choices regarding the type of care they receive. This systematic review included 35 studies and results indicated that consumer-directed care appears to increase client satisfaction with service use. However, the evidence reviewed was of low quality and the results did not support claimed improvements in clinical care outcomes. The range of choice that consumer-directed care provides can vary from selecting the type of services or service provider, to hiring and supervising care staff, and purchasing the services. The consumer-directed approach promotes client awareness, control and responsibility in their health and care process (Low et al., 2011). Despite these possible advantages, consumer-directed care is also perceived as potentially shifting costs to the consumer, impeding access to care and hindering consumer choice through barriers to appropriate information (Low et al., 2011; O'Dwyer, 2013).

The study by Low and colleagues (2011) concludes that the opportunities for exercising choice and control are central to clients' perceptions of quality, though this must be balanced with support in decision making and administration (c.f. O'Dwyer, 2013). Since the different models of care evaluated in this review have differing underlying principles, maximising quality within the care is most likely to be achieved through combinations of the principles underpinning each model (Low et al., 2011). From the client perspective, perceptions of quality in care were greater where care was delivered under the consumer-directed model. In contrast, the second systematic review also carried out by Australian researchers focused on narrative, rather than statistical outcomes. The review incorporated 17 studies exploring the evidence base for the shift toward consumer-directed care as a policy position in the delivery of community aged care (Ottmann, Allen, & Feldman, 2013). This study concluded that although the research on consumer-directed care has grown substantially in recent years, little remains known about the preferences and needs of older people who desire to maintain their independence and that future research should address this knowledge gap.

Summary

This review of the recent literature has highlighted several recurrent themes on clients' perceptions of the quality of care. Three studies identified quality as a product of broad aspects of care. Adams and Sharp (2013) distinguished between instrumental care and emotional care, separating the activities of care from the manner in which they are delivered. Similarly, Rodriguez-Martin and colleagues (2013) emphasised the need for both technical and emotional competences in the delivery of quality care. Gill and colleagues (2010) also continued the idea of quality emerging in the interpersonal and technical domains but added the importance of effective administrative arrangements for ensuring high standards of care delivery. Other authors also highlighted the importance of high technical standards of care (Bradshaw et al., 2012; De Bellis, 2010) as a means of providing good health and physical comfort as essential to enjoying life.

The importance of autonomy, individuality, independence, and the nature of interpersonal relationships are the most salient characteristics of the quality of care that emerge in qualitative studies where the focus is on the clients' perspective (Adams & Sharp, 2013; Aronson, 2002; Bradshaw et al., 2012; Nakrem et al., 2011; Rodriguez-Martin et al., 2013). Central to a client- centred view of quality is that the care is tailored to individual needs (Aronson, 2002; Chin & Quine, 2012; Dow, Sparrow, et al., 2013), involves nurturing physical contact, (Adams & Sharp, 2013; Bradshaw et al., 2012; Thomas et al., 2013), the ability to listen, closeness (Aronson, 2002), the ability to receive information about care (Alzheimer's Australia, 2013; Dow, Sparrow, et al., 2013; Harrison et al., 2014), empathy and sympathy (Bradshaw et al., 2012; Rodriguez-Martin et al., 2013), and respect for client values and preferences (Bradshaw et al., 2012; Eloranta et al., 2010; Ibrahim & Davis, 2013). Significantly, an undercurrent to these themes is the time available to provide such care (Armstrong et al., 2012; Aronson, 2002; Banerjee et al., 2012; De Bellis, 2010; Nakrem et al., 2012; Nakrem et al., 2011). This time pressure was expressed by a care worker in the study by Banerjee and colleagues (2012) who described having to ready 12 residents for breakfast within 45 minutes of commencing the shift.

Also significant in the literature, and related to the nature of personal relationships, was the issue of maintaining consistency in the provision of care (Aronson, 2002; Rosati et al., 2009). Clients sought a partnership and a sense of relationship with their care workers (Aronson, 2002; Bradshaw et al., 2012). In a US study on the effect of continuity and consistency of care personnel on client outcomes, consistency in care personnel was positively associated with decreases in the likelihood of client hospitalisation, and increases in independence with client activities of daily living (Rosati et al., 2009). This study shows tangible benefits for the utilisation of service resources and is consistent with findings from client-based studies that report higher quality of care being associated with positive and sustained relationships between clients and their care workers (Adams & Sharp, 2013; Aronson, 2002; Bradshaw et al., 2012; Nakrem et al., 2011).

Clients also valued opportunities for social attachment and engagement both within and beyond their home or residential facility (Bradshaw et al., 2012; Chin & Quine, 2012; Harrison et al., 2014; Thomas et al., 2013). These opportunities may include activities that maintain connectedness to spiritual, community and cultural practices (Bourgeault et al., 2010; Bradshaw et al., 2012; Haugan, 2014; Haugan et al., 2013). Clients also valued a home-like environment (Bradshaw et al., 2012) with access to private space (Aronson, 2002), and light, air, nature, and outdoor space (Chin & Quine, 2012) as part of that environment.

Finally, the circumstances of dying and death are an important aspect of the quality of care where clients seek high degrees of choice, autonomy and control (Alzheimer's Australia, 2013; Dow, Sparrow, et al., 2013). Having access to palliative care services, choice and information about end of life arrangements, and respect for those choices were significant factors in clients' perceptions of 'a good death' (Dow, Sparrow, et al., 2013 p. 238).

Opportunities for improvements in the quality of care based on client perspectives

The foregoing discussion has drawn attention to areas of care where clients perceive there to be deficiencies in their expectations that have a detrimental effect on their quality of life and well-being. The following suggestions focus on the process of care delivery but by necessity highlight the nexus between the nature of care and the systems through which it is delivered. The first opportunity for improving quality of care lies in training and skill development for care workers. Not only do care workers require training and skill development in the technical aspects of care, the evidence strongly suggests that there is a need to build emotional and social competencies for delivering that care.

The competencies of care workers can be enhanced, but in the absence of addressing factors that constrain the time that care workers have in which to provide care, the maximum potential benefits are unlikely to be achieved. The second opportunity lies in developing strategies that target the design of systems in which care services are organised to maximise the time in which to care. Insufficient time to care and poor work design not only constrain the quality of care for clients but also erode worker health, safety, well-being and commitment. Possible avenues may include modifying rosters (which could have benefits by also enhancing the continuity of care in worker-client relationships) or investigating ways in which units of care can be clustered or re-organised. These strategies are also likely to stimulate improvements in the technical aspects of care, through gaining a more comprehensive knowledge of clients' on-going and dynamic care needs. Aligned to having time to care are clients' desires for care routines to be designed for flexibility and choice.

The third issue is that aged care services are delivered in a system that clients perceive currently does not adequately balance choice with support (e.g. consumer-directed care). Client-based research makes a call for systems to better balance choice with support, through having access to information, advocacy and specialist services, such as palliative care.

Finally, the literature addressing the quality of care from the client perspective has highlighted subjective and qualitative aspects of care from which the development of measurable benchmarks is more challenging. As a result, benchmarks used to evaluate quality of care have tended to address clinical or health-related criteria. This review has not addressed the quality of clinical outcomes, or the ways in which they may be measured. However, evaluating the outcomes of the care process may provide valuable information on aspects of the care. It is the experience of good health and physical comfort that lays the foundation for enjoying life. A case in point is the use of restraints, which was highlighted as a significant issue in undermining the dignity, choice and rights of clients, particularly those with dementia. Examining the nature of events that lead to restraints could provide insight into the aspects of care that increase the risk of such events. Triggers in the environment that arise from inadequate care (such as hunger, boredom, over-stimulation, pain) are likely to exacerbate client restlessness, agitation, aggression and wandering that increases client distress and puts their safety

at risk. The frequency and occurrence of restraints, which often arise from workers' challenges in coping with difficult behaviours, may highlight intervention points for promoting quality of care that benefits the affected residents, those in proximity, and the staff. Similarly, Armstrong and colleagues (2012) provided the example of monitoring the use of incontinence aids as an indicator of care supporting activities of daily living. Other examples of possible indicators for the outcomes of quality care are the incidence of falls, wounds, infections; the use of medications for pain and behaviour management; and communication activities (Gladman & Bowman, 2012).

This review of the recent literature draws attention to the significant themes that constitute clients' perspectives on the quality of care. Important to clients in both the residential and community settings were maintaining a sense of individuality and independence, as exemplified through an ability to exercise autonomy, decision-making and control. Central to quality in life and care was the ability to build and maintain personal relationships, with care workers, family members and within the wider community. Community-based older Australians also seek to feel safe, comfortable and secure in their homes. In addition, 'higher order' needs such as being occupied (having something to do), social participation, control and dignity add meaning to life and need to be the focus of quality care (Netten, 2013).

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