Care Alliance Ireland

Guiding support for family carers

# Literature Review

## on the Relationship between Family Carers and Home Care Support Workers

November 2014

Care Alliance Ireland

## Acknowledgements

We express gratitude for the financial support of the Health Service Executive (HSE) and the Department of Community, Environment and Local Government, whose funding enables Care Alliance Ireland to undertake research of this kind.

We acknowledge the work of Ann Stokes, the primary author of this literature review.

We would like to thank those who gave feedback on early drafts of this report. We are grateful to international peer reviewer Licia Boccaletti of Anziani e Non Solo società cooperativa in Italy, as well as Nadine Henningsen (Canadian Caregiver Coalition) and Sandra MacLeod (Seniors Policy Division of Employment and Social Development Canada). Within Ireland, we are grateful to Kris Dhondt (RehabCare), Michael Doyle (Irish Wheelchair Association), Deirdre Shanagher (Irish Hospice Foundation) and Aoife Smith (Migrant Rights Centre Ireland). Particular thanks are due to Kieran Walsh (National University of Ireland, Galway) for his detailed and comprehensive feedback.

We also recognise the significant copy-editing work undertaken by Sandra Velthuis of Whitebarn Consulting.

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# Literature Review

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# Key Findings

Family carers provide unpaid informal help, usually to relatives with long-term illnesses, health problems or disabilities.

Home care support workers provide paid, formal care assistance to individuals who reside at home, but who need help with the activities of day-to-day living.

Ireland's population is ageing rapidly and the need for carers is increasing accordingly.

Most people with care needs (and their families) express a preference for ageing and dying at home and professionals back the benefits of this approach.

Family caring remains the mainstay of care for dependent people, but demographic and socio-economic changes mean that families find it increasingly difficult to provide care in the home on their own.

As a result, there is a growing demand for statutory and commercial and voluntary care services.

Government policy supports care in the home and enables it through a number of mechanisms, including the provision of home help and home care packages, but there are ongoing concerns about equitable access to quality services that are properly regulated.

Home-based care involves a number of different parties: the person in receipt of care; often at least one family carer; one or more home care support workers; and a range of other professional staff.

Although caring as a whole has been well-researched, far less attention has been paid to the dynamic of the relationship between the person being cared for, the family carer and home care support workers, with an almost complete absence of Irish research.

There is increasing recognition that models of care provision need to adopt a relationship-based approach, in preference to one that focuses solely on the individual in need of care and/or that only notes the division of labour between different roles.

Unfortunately, the literature rarely defines what is meant by 'relationship' and if/how this differentiates from 'interactions'.

Various enablers to quality relationships between home care support workers and family members have been identified, including, but not limited to: common goals; spending time together; continuity; honest communication; mutual respect; compassion; friendliness; reciprocity; and shared values.

Conversely, numerous barriers to positive relationships between home care support workers and family members have also been identified, including, but not limited to: lack of contact; disregard for expertise; unrealistic expectations; and the structure and approaches of associated professional services.

Researchers have formulated a number of models to promote optimum care situations that encompass the needs of the different stakeholders.

Researching the specific experiences of family carers in terms of their relationship with home care support workers, it has been found that they value services that are appropriate and competent, but that they consider positive relations to be equally important.

Researching the specific experiences of home care support workers in terms of their relationship with family carers, it has been found that the challenges posed by poor working conditions can negatively affect their ability to provide high quality care (this includes: lack of training; dirty work; workload pressures; unpredictable scheduling; unsocial hours; lack of supervision; feeling trapped; being taken for granted; low pay).

Home based care in a palliative context adds another layer of complexity to the dynamic between the person at the end of their life and their carers.

Migrant workers are major providers of home care; there are both positive and negative aspects to this and more research is needed in this important field.

Information and communications technology offers interesting opportunities to improve the relationship between people needing care, their carers and professional staff.

The roles of family carers and home care support workers are undeniably interlinked and the two systems of care need to be planned and implemented not alongside each other but together.

# Introduction and methodology

This document provides a review of literature on the relationship between family carers and home care support workers, in order to gain a deeper understanding of the body of knowledge that already exists in this subject area. Although it adopts an Irish perspective, this is naturally informed by research from other countries.

An initial literature search was carried out in March 2013. This process was then repeated in March 2014 and September 2014 to take account of feedback provided by reviewers and new developments in research and policy. On each occasion, the following electronic databases were used to find relevant articles in English: CINAHL, Google Scholar, PsycINFO and Science Direct. Further potential sources of information, such as discussion papers and policy documents, were sought from the Irish Departments of Social Protection and Health. A database of research on family caregiving, which is maintained by Care Alliance Ireland, was also examined.

A variety of individual terms and combinations of terms were used in the search, including 'relationship between family carers and home care support workers' and 'family carer experiences of home care support workers'. In searching, the word 'family' was substituted with 'informal', 'carer' was substituted with 'caregiver', and 'home care support worker' with 'home care provider'. The search was limited to literature on adults who need care, as opposed to research focusing on children's care needs.

The findings of the literature review were then analysed and are provided below under a number of subheadings, reflecting key themes that emerged during the process. Firstly, the scene for the review is set and an overview is provided of the background, policy context and nature of home care in Ireland. The importance of home care to the person being cared for is also examined. Data on both family carers and home care support workers are then analysed, focusing particularly on their relationship experiences in the provision of care within the home. The specific circumstances of palliative care and care provided by migrant workers are also addressed, before drawing a number of conclusions.

## Definitions

'Home care' is health and/or care support that is provided in the home, either by healthcare professionals or informally by family or friends (CARDI – Centre for Ageing Research and Development in Ireland, 2011). For Sims-Gould and Martin-Matthews (2010a), home care refers to the delivery of health and social services to individuals living in the community.

'Informal care' tends to be given by family or friends. Informal carers can be supported by state mechanisms such as allowances or grants, but the care itself is unpaid (CARDI 2011). The most recent Irish Census of Population (CSO – Central Statistics Office, 2012) defines a 'carer' as someone who provides regular unpaid personal help for a friend or a family member with a long-term illness, health problem or disability (including problems which are due to old age). The vast majority of respondents (98.3%) in research on full-time carers (Care Alliance Ireland, 2008) indicated that they were caring for a family member, hence the use of the term 'family carer'.

'Home care support workers' are employed to provide assistance to individuals living at home and because they are paid, they can be considered as formal carers (although their work is often at low pay and unregulated). They include home support workers, community health workers, personal support workers, home health aides and homemakers. They usually provide assistance with daily activities such as meal preparation, light household tasks and personal care.

## Background

Home care is received both by older and younger people. Everyone may require home care at times in their lives. For example, adults may need rehabilitation in the home after an accident, may develop a chronic illness that necessitates home care, or may need to be cared for at home due to age-related issues (Law Reform Commission, 2012).

Ireland's population is ageing rapidly. Census 2011 showed that there were 535,393 people aged 65 and over in Ireland, accounting for almost 12% of the population (CSO, 2012). People aged 80 and over made up 24% of those aged over 65. It is forecasted that the number of people aged 65 and over will rise from around 700,000 at present to 1,900,000 in 2041 (McGill, 2010). During the same time period, the number of people over the age of 85 will likely increase five-fold to around 355,000.

Taking 2006 as a base year, it was estimated that by 2016, there will have been a rise in demand for carers of more than 25,000, growing to 40,000 by 2021 (Carers' Strategy Consultation Group, 2008). These are respective increases of 17% and 28%. The Working Group on Long Term Care (2008) estimated that in Ireland in 2012, 41,700 people aged over 65 would need moderate care support (10.5 hours per week), 18,000 would need high care support (21 hours per week), and 40,200 would need continuous care (42 hours per week); this amounts to a total of 99,900 older people. As life expectancy increases, this figure is estimated to grow to around 129,000 by 2022 (Department of Health, 2011b).

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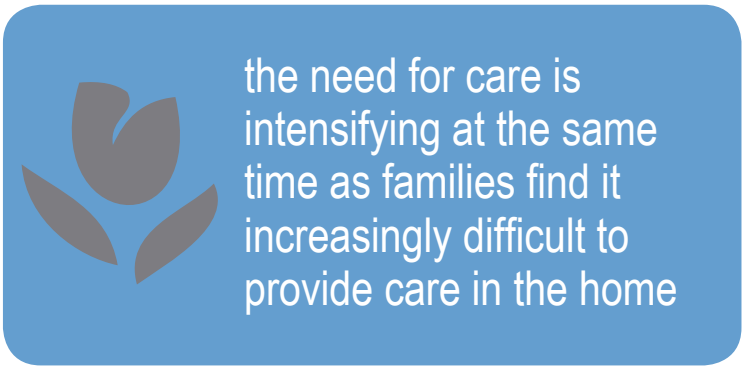
The projected demand for carers in Ireland is also determined significantly by the future population of those with an illness and/or disability who are resident at home. Demand for all day/daily informal home care by people aged 65 and over with disabilities is predicted to expand by 23,500 in the Republic of Ireland by 2021, representing a 57% increase over a decade (Wren et al, 2012).

Informal caring remains the mainstay of care for dependent people, with formal home care and residential care complementing this (National Economic and Social Council – NESC, 2012). It is estimated that every week, 8 million hours of care are provided by 274,000 family carers across Ireland (Care Alliance Ireland, 2013a).

The most recent Census revealed that 4.1% of the total population was providing unpaid assistance to others in April 2011 (CSO, 2012). It showed that the total number of carers aged 15 and over increased from 160,917 in 2006 (CSO, 2007) to 182,884 in 2011 (CSO, 2012); this 21,967 change represents a growth of 13.7%. Providing informal care can be enriching and rewarding where expectations placed on family carers are reasonable and adequate supports are provided (Care Alliance Ireland, 2013a).

Women have traditionally provided the majority of informal care to older people. As the proportion of women in the paid labour force increases, and family sizes become smaller, it is expected that less informal family care will be available in the future, and that the state will need to provide more support in this area (Working Group on Long Term Care, 2008). As there are now fewer adult children available to share the caregiving task than previously, the responsibilities for providing care may place greater pressures on individuals within families (Care Alliance Ireland, 2013a).

Thus, the need for care is intensifying at the same time as families find it increasingly difficult to provide care in the home. As a consequence, there is a growing demand for state governed and market-based and voluntary care services (Murphy & Turner, 2014).




Keeling (2014) contends that there is general agreement between patients, professionals and carers that the goal of home care is to enable individuals to remain in their homes safely, while receiving the services necessary to care for their condition-related needs, either following hospitalisation or to prevent admissions, and to facilitate aging in place. At an international level, there is a global shift towards blending care delivery within formal and informal environments as a direct response to economic and demographic pressures. *"Home care is at the hub of this activity, enabling people to age in place and keeping families intact."* (p. 63).

## Policy context and nature of home care in Ireland

Government policy in Ireland for older people, and for people with an illness or disability, is to support them to live in their own homes for as long as possible. Family carers are recognised as a key enabler for this. Government published a National Carers' Strategy in mid-2012 (Department of Health, 2012); this marked a significant milestone in the recognition of family carers (Care Alliance Ireland, 2012). The strategy defines government's key objective as follows: *"... to support them to live in dignity and independence in their own homes and communities for as long as possible. Carers are vital to the achievement of this objective and are considered a backbone of care provision in Ireland."* (p. 5). The first report on the implementation of the National Carers' Strategy (Department of Health, 2013) was also significant, but more for the lack of meaningful progress made. More recently, following considerable agitation by the community and voluntary sector, some progress has been made in terms of engagement with various government departments and suggestions for credible advancements in implementing the strategy.

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The growth in life expectancy and pressures on family carers outlined above are likely to result in a greater need for community-based health and social care services (Barrett et al, 2011). Given changing demographics and capacity limitations in the long-term care and acute hospital systems, the Department of Health, in its Comprehensive Review of Expenditure (2011a), acknowledged that community-based services will become a fundamental component in service delivery.

Domiciliary care in Ireland has changed dramatically over recent decades. Home care as a paid service was first introduced in Ireland under the 1970 Health Act (Murphy & Turner, 2014). However, this act specified that the state was to provide the service only where families, neighbours or voluntary organisations failed to provide support for an elderly person (Lundström & McKeown, 1994). Such voluntary services were mainly established and run by religious orders; they received discretionary funding from the state for doing so (Timonen & Doyle, 2007b). As public policy evolved and the benefits of home care were acknowledged, more home care supports became available (Law Reform Commission, 2012). Financial aid was provided to support informal carers and to purchase home care. In 2001, a state medical card was granted to all residents aged over 70 in Ireland, contributing to an increased demand for paid home care services (Timonen & Doyle, 2007b).

Home care is now a rapidly expanding sector of the Irish healthcare system. Barrett and Rust (2009) estimated a growth of 38% in health and social care worker numbers by 2028 and 50% by 2035.

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A recent report examining home care across Europe (Genet et al, 2013), identified the five key actors in home care in Ireland:

- The Department of Health, which is concerned with national strategy and overall budget and which reports to the Minister for Health

- The HSE, which is the operational arm of the Department of Health and responsible for implementing agreed strategy through four regional offices

- Provider organisations, including health services directly managed by the HSE, the large voluntary/non-profit sector (which has traditional links to the Department of Health) and the emerging private sector

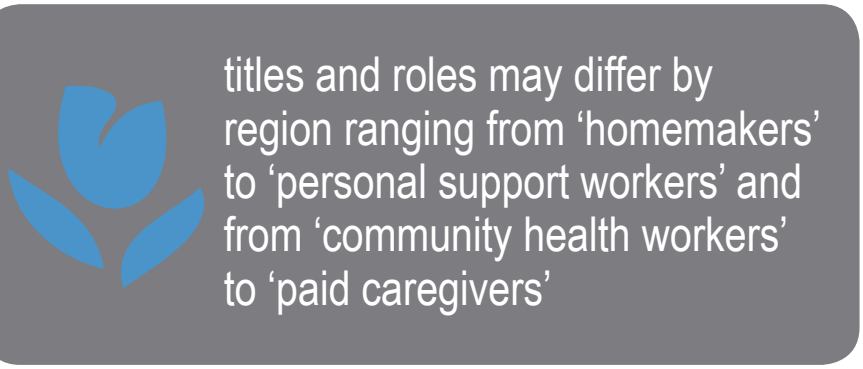
- Charities providing advice and support for clients and families (including Care Alliance Ireland)

- Professional organisations which influence standards and integration, such as the Irish Nursing Board, the Irish Medical Organisation and the Irish College of General Practitioners.

The above list is not complete; there is clearly a need for all health and social care stakeholders to be recognised, particularly home care support workers themselves. However, the infrastructure for effectively seeking their perspective does not currently exist.

Home care involves a wide variety of workers with different levels of training and qualifications. These include nurses, care managers, social workers, physiotherapists, occupational therapists and home support workers. However, there is no universal definition of 'professionals' for long-term care purposes. The term is usually related to the formal as opposed to the informal care sector and implies professional training for a specific role. In this sense, professionals can be distinguished from 'paid workers' who also operate in the formal long-term care sector, but who may not have specific training or a well-defined role (Triantafillou et al, 2010). Most home care workers provide services known as 'home support', typically non-professional services involving personal assistance with daily activities,

such as bathing, dressing, grooming and light household tasks (Sims-Gould & Martin-Matthews 2010a). Their titles and roles may differ by region, ranging from 'homemakers' to 'personal support workers' and from 'community health workers' to 'paid caregivers' (Lang et al, 2013).




Formal state-funded home care in Ireland consists mainly of home help and home care packages. Assessments for older people are carried out by HSE public health nurses and via the older persons managers of the HSE. Home care providers are then allocated hours to meet the tasks; any changes in service needs must be approved by the HSE. Home help hours used to be limited to non-personal care, such as cleaning, cooking and shopping, but increasingly, more personal care, such as bathing and dressing, is included. Home care packages do include personal care, and can also include medical care such as physiotherapy and chiropody (NESC, 2012). In 2011, the HSE spent €211 million on home help services and €138 million on home care packages (Duncan, 2011). During that year, 11,090,000 home help hours were provided to nearly 51,000 people, and 15,270 people received a home care package (HSE, 2012). Compared to 2010, the numbers receiving home help declined, while the numbers receiving a home care package increased. The Department of Health has indicated that 77% of home care package recipients are over the age of 75 (2011b). Overall, there has been a significant increase in the number of older people in receipt of formal home care in Ireland, from almost 16,000 in 2000 to a figure of over 66,000 a decade later (Timonen et al, 2012). This figure includes privately provided home care. Thus, whilst need may increase for home care, public provision may not. Numbers look set to continue to rise. The HSE Service Plan (2013) does commit to a strategic re-alignment of the model of care towards home care and community support services, suggesting a modest 2% increase in the provision of home care packages in 2014.

There is, however, no legal obligation on the HSE to provide a home help service, nor is there a set home care package. It is a resounding weakness of the Irish home care system that these services are not underpinned by legislation and are not provided on a statutory basis, compared with those in many other countries (for example: Australia, Denmark, France, Norway, Sweden and the UK). Where they are aware of them and where they can, people avail of statutory services, but outside of these, a considerable proportion of home care is purchased privately. On the demand side, lack of knowledge and confusion about entitlements to services combine to exacerbate supply-side inadequacies, leading to significant gaps in home care service provision to people in need. The Law Reform Commission (2012) has also pointed to the absence of a proper regulatory structure for the delivery of professional care in the home.

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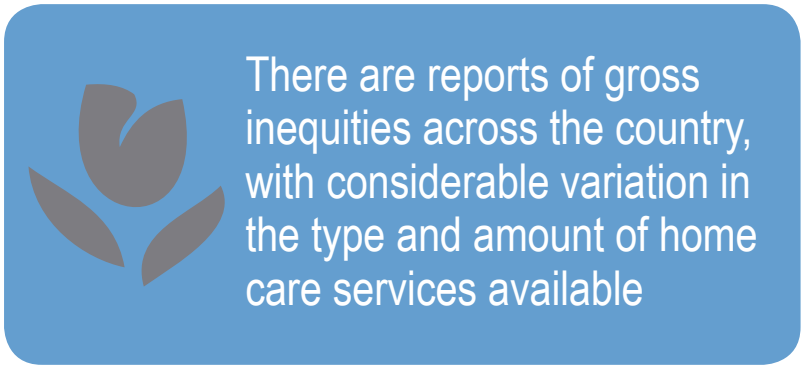
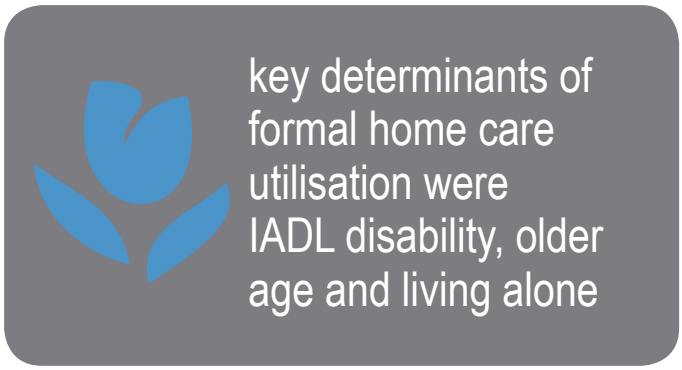
A further complication of home care is that it demands an integration of both social and healthcare services, but diversity in funding streams and organisational infrastructure promotes the fragmentation of these services (Keeling, 2014). Current economic cutbacks exacerbate the situation. For instance, home care staff are often not paid for travel time or costs ('mileage') between clients. Such cutbacks have a negative impact on service quality as they result in fewer home visits and follow-ups with clients and family. The job of home care has been identified as low-wage and low-statue by home care aides themselves (Butler, 2013). There have been reports of a 'grey market' in home care, with many of the staff being from immigrant communities and often untrained (Timonen & Doyle, 2007b).

Service delivery also varies regionally and access is influenced by 'squeaky wheels', whereby local politicians are approached to secure services. There are reports of gross inequities across the country, with considerable variation in the type and amount of home care services available (PA Consulting 2009). In 2010, in an attempt to bring greater consistency to the scheme, the HSE introduced National Guidelines and Procedures for the Standardised Implementation of the Home Care Package Scheme (HSE, 2010). These guidelines incorporated recommendations from the National Economic Social Forum (NESF, 2009), which had highlighted a

lack of uniformity in the manner in which the scheme had been implemented. It has been noted that there were regional variations in eligibility criteria, in maximum amounts payable per week and in the delivery of the packages themselves (NESC, 2012).




Population-based estimates of formal home care utilisation in Ireland have been made in The Irish Longitudinal Study on Ageing (TILDA). Murphy (2012) comments that the completion of the first wave of TILDA in February 2011 provided a platform for extensive investigation of formal home care utilisation. Formal home care was defined as the receipt of a home help service and of a personal care attendant service. In those aged 65 years and older, 8.3% (n=41,352) were found to utilise formal home care. In those aged 65 years and older, the key determinants of formal home care utilisation were Instrumental Activities of Daily Living (IADL) disability, older age and living alone.




In practice, home care services are delivered either directly through the HSE, through community and voluntary organisations, or through private providers. The HSE is increasingly outsourcing care work. The number of home care agency providers has increased significantly. In 2010, there were an estimated 150 companies providing home care in Ireland and there had been a 38% increase in private nursing home bed supply since 2003 (NESC, 2012). However, *"... budget reductions, with subsequent cutbacks in services, are having an impact on the extent to which service users are able to receive the services they need."* (p. 13).

In 2013, the HSE planned to support approximately 6,000 people (the majority aged over 65) with 10.3 million hours of home help and home care packages, either through direct provision or through contracted services (HSE, 2013). However, budget overruns in other areas of health spending resulted in acute pressure on home care supports 10 and noticeable cuts in home care services (Care Alliance

Ireland, 2013b). In addition, downward pressure on the hourly rates demanded by the HSE through its procurement procedures, raised significant concerns amongst not-for-profit providers about sustaining quality services (Care Alliance Ireland, 2013b).

Timonen et al (2011) note that a rapidly growing unregulated industry is burgeoning in Ireland, which is carving out a niche in the provision of more flexible and round-the-clock services. In 2012, the Law Reform Commission recommended that the Health Information and Quality Authority (HIQA) should be given additional regulatory and inspecting powers to ensure that ensure appropriate legal standards are in place for providers of professional home care, although it did not propose that HIQA regulation and inspection would apply to informal/family carers (Care Alliance Ireland, 2013b). The National Carers' Strategy set 2014/15 as an indicative timeframe to progress the development and implementation of national standards for home support services subject to inspection by HIQA. This action falls under the objective to promote the development of supports and services to protect the physical, mental and emotional health and well-being of carers. A Department of Health official at the Annual Carer Consultation Forum in November 2012 confirmed that home care provision will be subject to regulation, but not before 2016 (Care Alliance Ireland, 2013a).

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## The importance of home care support to older people

In a report for the World Health Organisation on home care across Europe, Tarricone and Tsouros (2008) outlined several good reasons for home care:

Many people prefer home care to any other option. Home is a place of emotional and physical associations, memories and comfort. Although many people can be happy in assisted-living facilities, retirement communities or nursing homes – and for many these are indeed better options – leaving home can be disruptive and depressing for some. When people are not feeling well, most want to be at home.

Home care also keeps families together, which is particularly important in times of illness. Home care prevents or postpones institutionalisation and may promote healing.

Home care allows maximum freedom for the individual, in contrast to institutions, which are regulated environments. Home care is personalised; tailored to the specific needs of each individual.

Home is an important *"therapeutic landscape"* for the individual (Keeling, 2014, p. 65). The sense of attachment, continuity, and normalcy associated with home care has been found to encourage feelings of well-being and enhance the efficacy of home care by offsetting the destabilising effects of illness (Williams, 2002; England & Dyck, 2011). Byrne et al (2012) describe research that has found that home support is perceived by older adults as key to facilitating their strong desire to remain in their own homes for as long as possible. According to Soodeen et al (2007) *"... unless a physical or cognitive impairment renders this setting unsafe, living in one's own home maximizes one's sense of security and autonomy."* (p. 1246). Sims-Gould and Martin-Matthews (2010b) note that an ageing population, combined with a strong desire to age in place, creates an increased likelihood that many elderly people will use home care. A range of different studies report that a large majority (between 67-80%) of the older population wants to die in their own home, but that in reality, only 26% does so (Murray et al, 2013).

Research has demonstrated that older people prefer toreceive home-based health and social care in their homes from home care workers rather than from other

unless a physical or cognitive impairment renders this setting unsafe, living in one's own home maximizes one's sense of security and autonomy

health professionals, including nurses (Twigg, 2000). Sims-Gould and Martin-Matthews (2010b) state that there is also body of research that shows that the tie between home support workers and clients is important and that they can develop a set of familial-like expectations and bonds that extend beyond the role of a paid employee (citing Piercy, 2000, for example).

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CARDI (2011) refers to a 2009 survey of older individuals in Northern Ireland who were using home care services; the activities that most indicated they were not able to perform were household shopping (79%), housework (79%) and preparing food (57%). The activities that most received help with were dressing (66%), washing themselves (63%) and preparing food (59%). The same survey showed that 29% of older people felt that home help made them 'a lot more independent', whilst almost half (48%) said that it made them 'a bit more independent'.

In 2013, Russell et al (2013) examined whether continuity in the provider of home health aide services was associated with the likelihood of improvements in Activities of Daily Living 12 (ADLs). They retrieved clinical and administrative records from a population receiving home health aide services at a large, urban, not-for-profit, Medicare-certified home healthcare agency in the US (n=16,541). Results revealed that cases which had high levels of continuity in the provider of home health aide services had a significantly greater likelihood of improvement in ADLs compared to cases with low levels of continuity.

Keeling (2014) comments that home care studies have tended to focus on a limited aspect of home care, namely recipient characteristics and the organisation of home care.

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*"To harness current knowledge more effectively and bring about better outcomes, a uniform framework and methodology for researching home care is needed. A vital ingredient ... [is] an understanding of the patients' needs for home care."* (p. 64). Several studies have been conducted into what constitutes good quality care for older people in the home.

Patmore (2002) highlighted that an individual-centred approach to home care is essential for ensuring good quality service. Older people are not a homogeneous group and they differ substantially in their values and preferences for home care; consequently, their opinions should be taken into account in developing individual-centred care. A study by Patmore and McNulty (2005) based on interviews with older people and home care staff, identified a list of key factors for promoting flexible, person-centred home care. These included: regular provider staff who can get to know the home care recipients well and who believe in caring for the whole person; sufficient time allowed so that visits are not rushed and quality time is spent with recipients; flexibility for staff to offer extra help when required; staff rewards and a manageable workload so that good quality staff can be recruited and retained.

individuals involved in the delivery of home support services are thus in a key position to support the personhood of older adult clients

Byrne et al (2012) argued that client perspectives of home support have not been considered in relation to personhood, which they define as *"a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being"* (p. 377). They undertook secondary analysis of data from a generic qualitative study including 82 semi-structured interviews with older adult home support clients in British Columbia, Canada. Findings revealed that clients value a focus on the person, preservation of autonomy and interactions characterised

by recognition, validation, collaboration and negotiation. They concluded that individuals involved in the delivery of home support services are thus in a key position to support the personhood of older adult clients.

Watkinson-Powell et al (2014) explored barriers and facilitators to food provision for older people receiving home care in northern England. Their results provide additional evidence on the challenges associated with creating positive relationships. Thematic analysis of semi-structured interviews with nine home care workers revealed that significant time pressures limited home care workers in their ability to socially engage with service users at mealtimes, or provide them with anything other than 'ready meals'. They concluded that the potential role for home care workers in promoting good nutrition in older people is undervalued and undermined by the lack of recognition, training and time dedicated to food-related care.

the potential role for home care workers in promoting good nutrition in older people is undervalued

## Towards an understanding of the relationship between family carers and home care support workers

Whilst there is extensive literature on the importance of partnerships between formal and informal care systems, much of this work has focused on 'professional' formal care providers such as nurses and social workers. There are few published studies that examine the specific relationships within care work dynamics between family carers and home care support workers.

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Gantert at al (2009) point out that *"... models of care provision have shifted away from the more individualistic 'person-centred' or 'client-centred' approaches that tend to focus on the client (Post, 2001) and towards models such as the 'partnership approach' (Adams & Clarke, 1999) and 'relationship-centred care' (Nolan et al, 2004) ..."* (p. 46), which extend care relationships to include clients, family caregivers and others involved in the client's care management. In responding to this shift, they argue that providers have had to relinquish their traditional expert approach (Qureshi et al, 2000) and adopt a more relational orientation, based upon mutual respect, equity and shared understanding (Clarke, 1999). In-home provider/family caregiver relationships are an essential component of care provision, as healthcare providers and family caregivers are required to coordinate their efforts to ensure that older people's care needs are met on an ongoing basis to allow them to remain at home (Ward-Griffin, 2001).

extend care relationships to include clients, family caregivers and others involved in the client's care management

Guberman et al (2006) note that while many studies have examined the relationship between home care practitioners and their clients, far fewer have explored the relationship between the former and informal caregivers, despite their strategic role in care. They contend that this relative lack of interest can probably be attributed to the ambiguous status given to caregivers within home care policies and services.

Sims Gould and Martin-Matthews (2010b), as part of their own research, also undertook an extensive literature review of research conducted to date. They felt that little is known about what aspects of home support services assist family caregivers or hinder them in their caregiving. They recognised the substantial body of

literature that discusses the importance of partnerships between formal (paid) and informal (family) systems of care (Brereton & Nolan 2003; Guberman et al, 2006; Lyons & Zarit 1999; Penning & Keating 2000; Stone & Dawson 2008; Ward-Griffin 2002; Ward-Griffin & Marshall, 2003; Wiles, 2003). However, they pointed out that the bulk of this research focuses on professional formal care providers such as nurses, physicians and social workers. They concluded: *"While the relationship between formal and informal care has been clearly established in the literature, there have been few published studies beyond those mentioned above that examine the relationship dynamics between home support workers and family caregivers."* (p. 416).

> relative lack of interest can probably be attributed to the ambiguous status given to caregivers within home care policies and services

According to Gantert et al (2009): *"The successful implementation of partnering and relationship-centred approaches to home care calls for a greater understanding of family caregivers' perceptions of their relationships with in-home providers"* (p. 46). They contend that much of the literature addressing relationships between family caregivers and healthcare providers has been conceptualised in terms of a division of labour between the two roles (citing for example, Duncan & Morgan, 1994). They further argue that only a few studies have explicitly examined relationship-building amongst healthcare providers and family caregivers (citing for example, Clark et al, 1995; Scharer, 1999; Ward-Griffin et al, 2003), and that virtually nothing is known about how family caregivers perceive relationship-building with providers during the delivery of home care.

Sims-Gould and Martin-Matthews (2010b) believe that: *"An integral step in advancing understandings of caregiving is an examination of the contributions of, and interfaces between, family caregivers and paid home support workers. Home support is the only type of health service that can in theory provide exactly what family members provide and vice versa ... A deeper understanding of the relationship between the two systems of care will improve our knowledge regarding the strengths and limitations of each system. It will also help provide insight into ways to enhance their integration and complementarities"* (p. 416).

Gantert et al (2009) believe that there is a gap between theory and application. They cite early work which found provider/family caregiver interactions to be non-existent (for example, Fischer & Eustis, 1994). They also argue that other studies have shown that the relationship is ambiguous and characterised by tension and

power struggles (McWilliam et al, 2001; Ward-Griffin, 2001; Ward-Griffin et al, 2003; Ward-Griffin & McKeever, 2000). Guberman et al (2006), in Canada, found that care practitioners tend to perceive the work of caregivers as mainly instrumental and clinical, ignoring family relations that tie them to their relatives. Whilst aware of the difficulties and negative impact experienced by caregivers, the majority of practitioners had high expectations surrounding caregiver participation in treatment plans, albeit as quasi nurses' aides.

seldom within the research is 'relationship' defined or differentiated from 'interaction' – relationships are viewed as an almost inevitable outcome of interactions, instead of something that all parties are involved in building

On the other hand, Funk and Stajduhar (2013) note that previous research has found that relationships between healthcare workers and family members are commonly characterised by feelings of commitment, closeness (when a provider is defined as 'one of the family', as in, for example, Piercy, 2000) and trust (for example, Thorne & Robinson, 1989). They also cite Gantert et al (2008), who characterised the relationship as *"encompassing affective, cognitive, and behavioural components relevant to all aspects of provider-client interactions"* (p. 24). However, they believe that a major issue within the literature is a lack of conceptual consensus and theoretical grounding. For example, seldom within the research is 'relationship' defined or differentiated from 'interaction' – relationships are viewed as an almost inevitable outcome of interactions, instead of something that all parties are involved in building (citing Piercy & Wooley, 1999).

Funk and Stajduhar (2013) undertook an extensive review of research on the relationships between healthcare workers and family members and found that quality relationships have been associated with various features. They found that having contact, time together and continuity was found to be important (Caron et al, 2005; Gladstone & Wexler, 2002; Hertzberg & Ekman, 2000; Lynn-McHale & Deatrick, 2000; Piercy, 2000). Honest communication and information sharing were also found to be key (Hertzberg & Ekman, 2000; Lynn-McHale & Deatrick, 2000; Piercy, 2000). Mutual knowing was also significant (Lynn-McHale & Deatrick, 2000); this includes the home care provider understanding the individual needs of the client (Caron et al, 2005). They also noted that good relationships have been found to be further facilitated by a common goal (Duncan & Morgan, 1994; Gladstone & Wexler, 2002; Hasselkus, 1988; Hupcey, 1998), shared experiences (Gladstone & Wexler, 2002) and

respect, appreciation and recognition (Duncan & Morgan, 1994; Hasselkus, 1988; Lynn-McHale & Deatrick, 2000). Whilst a balance of power may also be salient, it may be difficult to attain in practice (Ward-Griffin & McKeever, 2000). Willingness to participate in the relationship has also been found to be important (Lynn-McHale & Deatrick, 2000; Piercy, 2000). Expressed empathy (Caron et al, 2005), feelings of closeness and trust (Gladstone & Wexler, 2002; Lynn-McHale & Deatrick, 2000) and reciprocity, reliability and consistency have also been suggested as influencers of relationships, or perhaps more correctly, as being an outcome of good relationships (Lynn-McHale & Deatrick, 2000). Similarities have also been found to facilitate relationships (Piercy, 2000), including using the same language (Lynn-McHale & Deatrick, 2000); having the same values and assumptions (Hasselkus, 1988) and shared expectations of roles (Duncan & Morgan, 1994; Nolan & Dellasega, 1999; Schwartz & Vogel, 1990; Ward-Griffin, 2001; Ward-Griffin & McKeever, 2000).

providers can build relationships with family caregivers by offering emotional and cognitive support, being friendly and caring, communicating effectively and establishing trust

Gantert et al (2009) also conducted an extensive review of existing literature on the relationship between family carers and care providers. They identified numerous facilitators of relationship-building among providers and family caregivers. For example, providers can build relationships with family caregivers by offering emotional and cognitive support, being friendly and caring, communicating effectively and establishing trust (Clark et al, 1995). They pointed to research indicating that provider/family caregiver relationships may be facilitated by providers who are empathetic, supportive, encouraging (Laitinen & Isola, 1996), non-judgemental, positive in their expectations, and willing to spend time with, and engage with, family caregivers (Scharer, 1999). They also highlighted that relationships are facilitated by providers who are concerned, appreciative, compassionate and welcoming, who take family caregivers' opinions seriously and who regularly provide feedback (Hertzberg & Ekman, 2000; Ward-Griffin et al, 2003). Moreover, they found that family caregivers' positive expectations, as well as readiness and willingness to engage with providers, served to promote relationship-building (Scharer, 1999).

Gantert et al (2009) also noted that barriers to provider/family caregiver relationships have been examined. These include a disregard by providers for

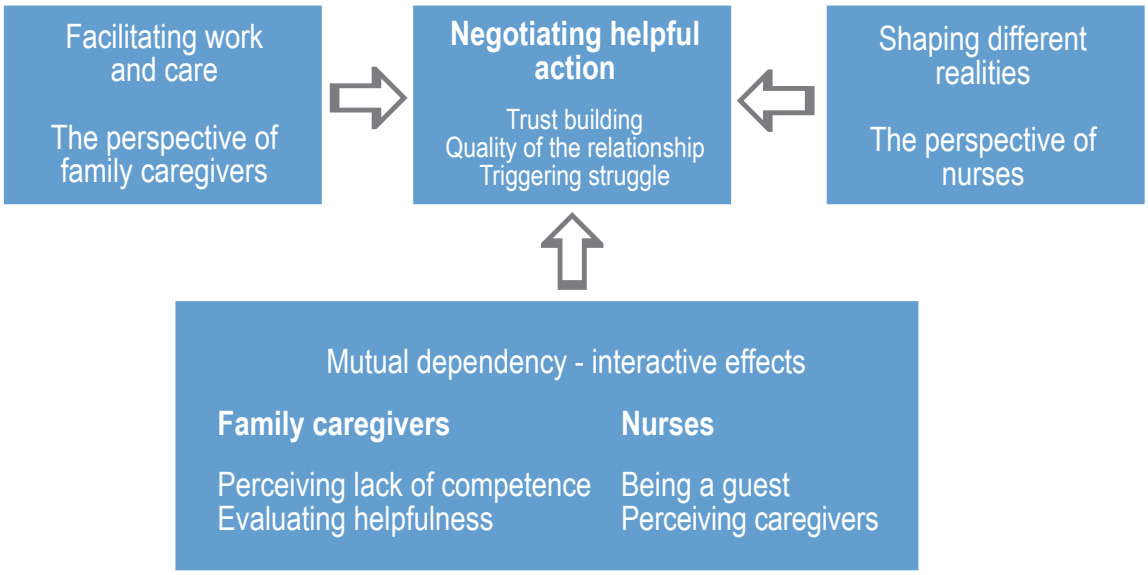
family caregivers' knowledge and expertise (Duncan & Morgan, 1994; Gilmour, 2002; Hertzberg & Ekman, 2000; Ward-Griffin et al, 2003), lack of contact with family caregivers (Hertzberg & Ekman, 2000) and strict adherence to a division of labour (Duncan & Morgan, 1994; Ward-Griffin et al, 2003). Relationship-building has also been found to be hindered by ineffective communication (Gilmour, 2002) and by providers' negative and incongruent expectations of family caregivers (Scharer, 1999). Other impediments include the absence of family caregivers when healthcare providers are present in the home and family caregivers' lack of respect for, or unrealistic expectations of, healthcare providers.

Despite implicit assumptions in much of the research that the involvement of nurses in home care arrangements is inherently beneficial, there is evidence that their involvement may in fact have a destabilising effect. Büscher et al (2011) undertook a study in Germany to investigate the relationship between nurses and family caregivers and its impact on the care provided. Interviews were conducted with family caregivers (n=57) and nurses (n=31) and analysed using grounded theory methodology. It was found that the relationship between formal and informal care was an encounter of two rather different perspectives. The perspective of family caregivers was focused on establishing a home care arrangement that allowed for the goal of facilitating work and caring for their sick family member. Family caregivers were found to dedicate their efforts towards an arrangement in which the care recipient's needs were taken care of and which allowed for the best possible division of work and care, but always in the best interest of the care recipient. In contrast, the nurses' perspective was not a goal, but the performance of work characterised by a process that was conceptualised as shaping different realities in different homes. Together, these two perspectives of formal and informal care influence the negotiation of helpful action (see Figure 1). Thus, the relationship between nurses and family caregivers is not static, but has an implicitly dynamic nature. If family caregivers and nurses do not agree on what is best for the care recipient, there is potential conflict concerning the question of who best advocates for the care recipient and who acts in his or her best interest. Ultimately, it is argued that trust, cooperation and negotiation are essential aspects when building optimum relationships between formal and informal care. The authors conclude that to provide sufficient support in home care, nurses need the ability to engage in negotiation processes that take the whole home care arrangement into

trust, cooperation and negotiation are essential aspects when building optimum relationships between formal and informal care

account. They recommend that developmental work is needed to design services that are helpful for family caregivers. Similarly, earlier work conducted by Wiles (2003) emphasised that family caregivers experience home support as a *"constantly negotiated process"* (cited in Sims-Gould & Martin-Matthews 2010b, p. 105).

**Figure 1: Negotiating helpful action – the relationship between formal and informal care (Büscher et al, 2011)**



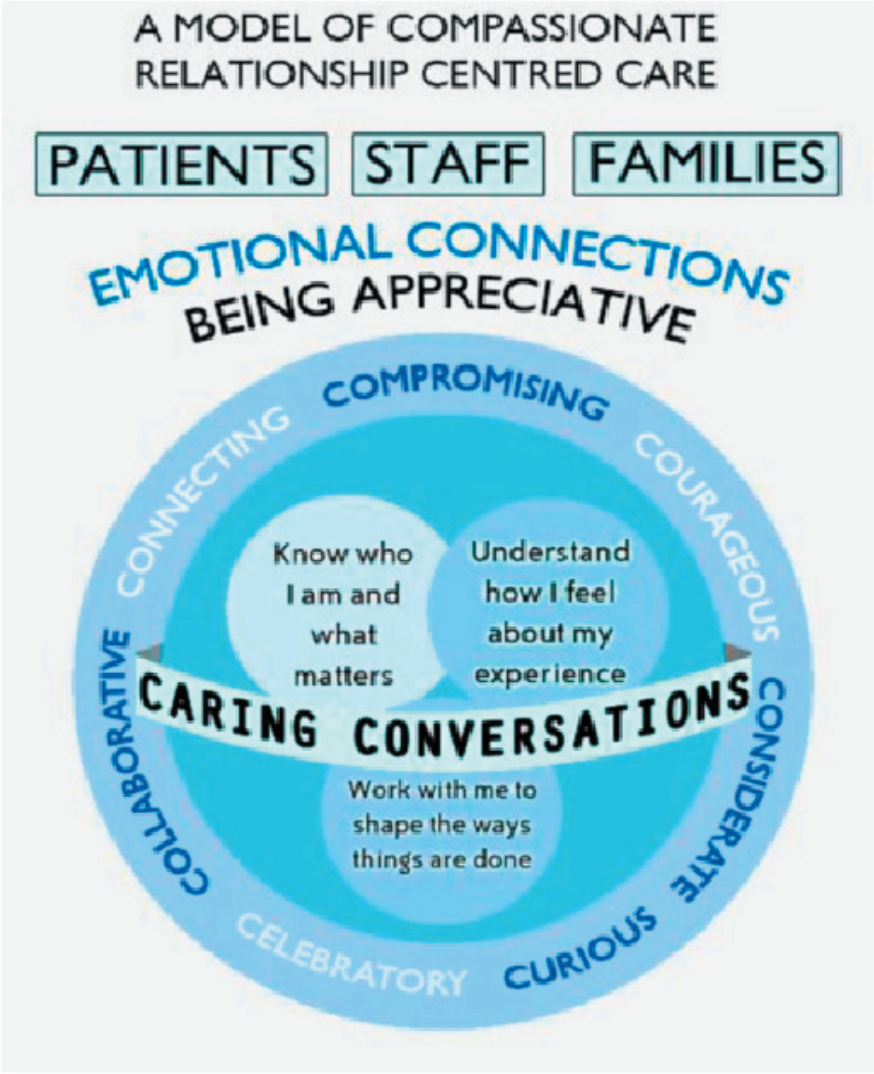

Triantafillou et al (2010) examined policy developments targeting informal carers within long-term care systems in several European countries. They found that relationships between informal carers and professional formal carers were substitutive as opposed to complementary, for two main reasons: the unequal sharing of care duties and the unequal caring status of informal carers and professionals. The infrastructure of the health system is designed in such a way that it separates informal and formal caregivers, as opposed to bringing them together to provide higher levels of care. They proposed two solutions to increase the value of informal caregivers and create a more equal and balanced relationship between healthcare professions and informal carers, namely: information and education of cared-for and caring people and the use of home care services.

Lang et al (2013) recommended the consideration of client-centred home care models that provide quality and sustainable home care. In particular, they advised a model of care whereby each household has a professional primacy care coordinator to facilitate seamless care and to ensure routine assessments of caregivers' health and well-being as part of the home care.

As a consequence of their research in the UK, Dewar and Nolan (2013) proposed a model for the development of compassionate relationship-centred care between

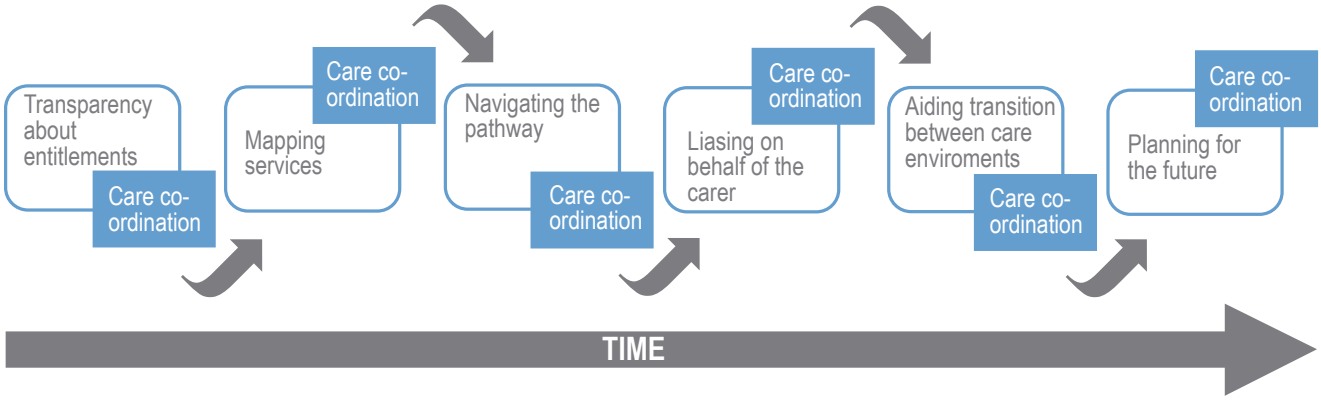
older people, relatives and staff in acute hospital settings. Although focused on a hospital setting, their findings may be adapted to the home care context. They conducted an inquiry that encompassed a range of methods including participant observation, interviews, storytelling and group discussions involving older people (n=10), staff (n=35) and relatives (n=12). They identified seven factors necessary to promote appreciative caring conversations (the 7 Cs model – see Figure 2): being courageous; connecting emotionally; being curious; collaborating; considering other perspectives', compromising, and celebrating.

**Figure 2: Model of compassionate relationship centred care (Dewar & Nolan, 2013)**



McPherson et al (2014) explored the connection between informal and formal carers in New Zealand with the aim of identifying how a positive connection may be developed and maintained. They undertook a qualitative study using focus groups and individual interviews with informal carers (n=39), formal care service providers (n=23) and representatives from carer advocacy groups (n=8). Four key themes emerged from the analysis: quality of care for the care recipient; knowledge exchange valuing the carers' perspective; one size does not fit all; and reducing the burden services add. They also proposed an optimum interface 18 to address these key areas (see Figure 3) and concluded that specific structures and processes to support a more positive interface are warranted if informal carers and services are to work together.

**Figure 3: An 'optimum' interface: engaging with the carer (McPherson et al, 2014)**



## Family carers' relationship experiences with home care support workers

Funk and Stajduhar (2013) found that family members providing care at home appreciate formal services and providers that are competent, flexible, individualised, coordinated, consistent and accessible. With adequate information, such care can provide a sense of security and safety (Attree, 2001; Funk et al, 2009; Goldschmidt et al, 2006; Milberg & Strang, 2007; Morss Dy et al, 2008; Öhlén et al, 2007). Perceptions of quality healthcare (competence, helpfulness, responsiveness to care recipient needs) have been shown to generate feelings of being genuinely cared for, and about, as well as better, more trusting and mutually affectionate relationships (Attree, 2001; Caron et al, 2005; Friedemann et al, 1997; Gladstone & Wexler, 2002; Hertzberg & Ekman, 2000; Hupcey, 1998; Lynn-McHale & Deatrick, 2000). Beyond direct care and support, interpersonal and relational aspects of care are definitely seen as important, including compassionate, friendly attitudes and behaviours of the paid care worker that convey 'caring about' and commitment to the family, as well as interactions that generate feelings of trust, rapport, being understood and valued, comfort and mutual affection (Attree, 2001; Morss Dy et al, 2008; Piercy & Wooley, 1999; Steinhauser et al, 2000). Funk and Stajduhar (2013) argue that *"Connections between relationships, trust, and perceptions of care quality appear important, though underresearched. Whereas perceptions of quality care might influence perceptions of relationships, it is plausible that trusting relationships influence care perceptions"* (p. 191).

having a positive experience with paid home care providers meant a great deal to family caregivers ... with competent help, they could enhance the quality of life of the persons for whom they cared, and they in turn felt more competent as caregivers themselves

In the US, Piercy and Dunkley (2004) investigated, via two studies, the meaning of paid home care for family caregivers of frail older adults, comparing and contrasting what good and poor quality home care means to their caregiving efforts. Qualitative semi-structured interviews were conducted with 15 caregivers in their first study in order to explore their experiences of healthcare providers. In their second study, 20 non-spouse caregivers were interviewed about both positive and negative experiences with home care providers. Data from the two studies were then combined. The authors found that having a positive experience with paid home care providers meant a great deal to family caregivers. Respondents found that with competent help, they could enhance the quality of life of the persons for whom they cared, and they in turn felt more competent as caregivers themselves. Enhanced quality of life for care recipients was achieved by: helping to maintain their dignity (through performing personal care tasks considered embarrassing by either a child

caregiver or a parent care recipient); helping care recipients maintain physical or psychological independence; and performing needed tasks that a caregiver was unable to do so that care recipients could stay in the community. Paid providers also helped caregivers feel more competent in caring for their relatives through providing respite, maintaining a supportive relationship with caregivers, teaching them new skills, and providing help to the caregivers to navigate the healthcare system. In contrast, when paid workers were seen as incompetent or unreliable, caregivers in this study reported increased stress and workload. As a consequence, their ability to care for their elderly relatives in the community was compromised by these situations, and caregivers frequently made efforts to find different workers or companies that could provide better quality services. They concluded that caregiver circumstances, as well as care recipient needs, should be considered in making decisions about who receives formal home care services.

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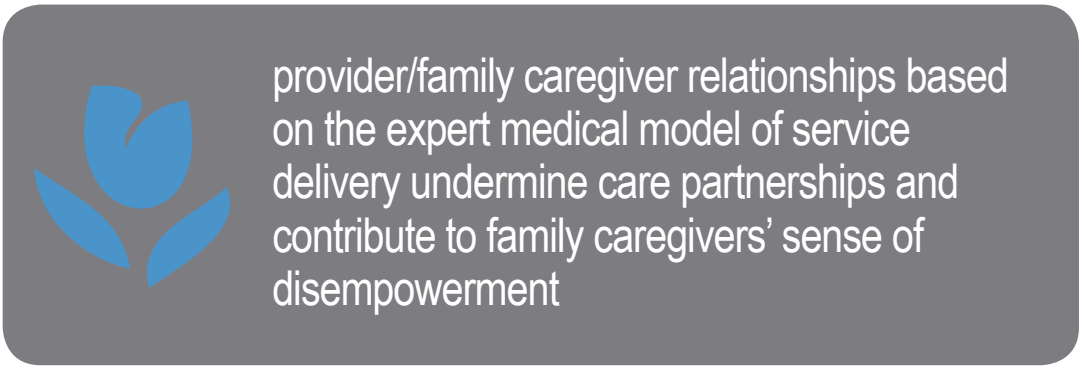
Soodeen et al (2007) conducted a qualitative study on experiences in home care from the perspective of older physically impaired individuals (n=9) and their caregiving spouses (n=9) in Canada. Separate face-to-face semi-structured interviews were carried out with each spouse. Analysis of the interview data revealed four themes. For care receivers, the themes were independence and developing a trusting relationship with home care workers. Relief and continuity were voiced by the caregiving spouses. The authors showed how these themes relate to the participants' sense of security, which emerged as a key underlying concept in the home care experience. They also found that for caregiving spouses, home care promoted their independence; sharing their responsibilities with a skilled worker provided temporary relief from the intensity of the caring situation and allowed them a short time to go out or do something for themselves. Both care recipients and caregiving spouses emphasised the relational nature of home care and how good long-term relationships with their care workers made for an overall

positive experience. These perspectives were shared by participants regardless of their specific care needs or the services received. Importantly, this study shows that home care is about more than service delivery it is also about relationships. The value of home care workers in their clients' lives cannot be understated. Sims-Gould and Martin-Matthews (2010b) subsequently found fault with this study, for they felt that the authors had not explicitly examined the relationship dynamics between paid workers and family members.

Gantert et al (2009), as part of their review of research to date, found that family caregivers and providers are not always successful in establishing a positive relationship. For instance, they cited the work of Ward-Griffin et al (2003) who found the provider/family caregiver relationship to be characterised by an imbalance of power and status, with providers taking power over and limiting the input of family caregivers. In addition, they referred to the work of McWilliam et al (2001) who found that provider/family caregiver relationships based on the expert medical model of service delivery undermine care partnerships and contribute to family caregivers' sense of disempowerment. They also referenced research findings that suggest that conflicting roles and expectations can place strain on provider/family caregiver relationships and can contribute to the exploitation of family caregivers (for example, Ward-Griffin, 2001; Ward-Griffin & McKeever, 2000).



The purpose of Gantert et al's (2009) study was to explore, from a Canadian perspective, family caregivers' perceptions of relationship-building with healthcare providers, including the barriers to, and facilitators of, this experience. Applying interpretive phenomenology, the authors conducted in-depth qualitative interviews with a purposive sample of 11 family caregivers. Results showed that family caregivers perceived their relationship-building with in-home providers as a holistic, interconnected and dynamic process consisting of three components. Relationship-building began with reluctantly making essential connections. Relationships developed through two other relational components: getting to know each other and finding ways to work together. There was movement from one component of the relationship-building process to another, with facilitators and barriers encountered at both contextual and individual level. They also identified two contextual barriers and facilitators, namely (not) having/making time and (not) having continuity of provider. The authors recommended that: *"For relationship-building to occur, family caregivers and providers must connect with each other. The mere presence of both family caregivers and providers in the home at the same time does not always lead to the formation of relationships, while the absence of family caregivers removes even the possibility of relationship-building"* (p. 60). They also argued that if quality in-home service is to be optimised, administrators and decision-makers must consider the possibility that the costs incurred in affording more staffing time for the development of provider/family caregiver relationships may be offset by more timely and personalised care delivery to seniors. *"Most importantly, the findings of this study illuminate the role of family care-givers as invaluable partners in care and invite providers to attend to relationship-building efforts with family caregivers in the pursuit of this aim."* (p. 60).

the costs incurred in affording more staffing time for the development of provider/family caregiver relationships may be offset by more timely and personalised care delivery to seniors

A study by Sims-Gould and Martin-Matthews (2010b) sought to examine the contributions and the dynamics between family caregivers and home support workers in another Canadian context. They analysed data from in-depth interviews with family caregivers (n=52) who had an older relative in receipt of home support services in British Columbia in the previous 12 months. Themes relating to direct care (care provided directly to the elderly person) and assistive care (care provided

the two systems of care (the formal paid system and the informal unpaid system) do not run parallel to one another but are inextricably interconnected

to one caregiver by another) were identified. In discussing the direct care provided by workers, family members emphasised dissatisfaction with instrumental assistance provided by home support workers while also stressing the importance of affective assistance. In commenting about assistive care, three key themes emerged: caring together, care management, and quality assurance and monitoring. The results of this study show that the two systems of care (the formal paid system and the informal unpaid system) do not run parallel to one another but are inextricably interconnected. While workers, directed by a plan of care, provide care to their older clients, they also provide assistance to, and receive assistance from, their clients' family members. The boundaries between what families provide and what home support workers provide are therefore often not as clear cut as agency policies might dictate.

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Byrne et al (2011) undertook a further qualitative study in Canada in order to gain feedback about satisfaction of home care service organisations with care from clients and their families. Interviews were conducted with older adult clients (n=82) and family members (n=52). In most cases, clients and families were very positive about home support services, barring one or two specific issues with care that detracted from their care experiences. A large subgroup of participants (n=39) provided 'contingent' satisfaction responses, reflecting the duality of perceptions that clients and families convey about services. Three themes emerged as critical to understanding these types of responses: adept versus inept staff; predictable versus precarious scheduling; and responsive versus restrictive care plans. Specifically, whilst some family carers felt positive about their workers, they were simultaneously negative about agency staff, management and care plans that resulted in restrictions to the care they received. Several participants also discussed how some workers were better than others based on skills, training, experience and

personality, which meant their perceptions of services could potentially change from one day to the next. Still others reported having been satisfied in the past, but cutbacks to the type and quantity of services offered influenced their perceptions of home support. The authors conclude that *"an understanding of the reasons for contingent responses are important in helping home care agencies to target quality improvement initiatives for individual clients and families"* (p. 174).

## Home care support workers' relationship experiences with family carers

From qualitative interview data gathered from a group of community-based dementia care workers (n=7) in the UK, Ryan et al (2004) sought to identify sources of job satisfaction and reward. Interviews were conducted with the workers at two points in time and the data were analysed using a case by theme matrix approach. The results indicated that there were high levels of job satisfaction amongst the group, which were enhanced by several factors, including: good organisational support; day-to-day autonomy; the ability to maintain relationships with people with dementia and their families; and staff's feelings of contributing to and improving the status and quality of life of people with dementia. The service was not generously funded, nor particularly well staffed. However, it was developed in direct response to the needs of people with dementia and their carers, was committed to a philosophy of genuine partnership working, and was valued by the organisation in which it was based. *"Herein, it seems, lie the seeds of a culture that we desperately need to nurture and grow."* (p. 118).

Not all experiences are similarly positive. For example, Wibberley (2013) examined the problems of a 'dirty workplace' in domiciliary care. While dirty work is an acknowledged part of domiciliary care, involving tasks such as bathing and toileting, the author contends that there has been little examination into whether the workplaces in which home care is provided may also be physically dirty spaces. She argues that dirty workplaces have a negative effect on domiciliaries by unofficially increasing their workload, in terms of workplace management, undertaking domestic tasks and managing their own health and safety. However, workers may feel that they have little choice, due to the needs of the client, the demands of the job or for their own well-being. She points out that *"the unrecognised nature of these tasks creates further devaluation of the work carried out by domiciliaries"* (p. 161).

Although not specifically examining the relationship between home care workers and family carers, a recent study by Sims-Gould et al (2013) provides important evidence on the challenging context in which they provide care, and should thus be taken into consideration.

Semi-structured interviews were conducted to explore the nature, type and management of crises from the perspective of home support workers (n=118) of older persons in British Columbia, Canada. It was found that the delivery of home healthcare occurs within a context of unpredictability related to scheduling, time constraints, variability of client need and changing work environments.

Swedberg et al (2013) undertook research that examined both the challenges associated with creating positive relationships between family carers and home care support workers and the strategies used to overcome obstacles. They completed a

the delivery of home healthcare occurs within a context of unpredictability related to scheduling, time constraints, variability of client need and changing work environments

qualitative study to investigate the work experience of Swedish healthcare assistants and to explore how they managed when delivering 24-hour care. The findings from their interviews with healthcare assistants and field observations in patients' homes revealed a number of barriers for healthcare assistants that affected both their working conditions as well as patient care. The first of these was a competence gap; healthcare assistants named lack of training, no prior experience and difficulties with learning in the workplace. Poor working environments and feeling mastered by the patient led to healthcare assistants experiencing the emotion of being trapped in the home setting. Poor supervision of care staff was viewed as a consequence of a lack of formal leadership and unclear routines. Finally, in being unconnected to the patient care system, healthcare assistants named a lack of coordination of patient care and being left alone as barriers. The authors found that healthcare assistants used four types of compensatory strategies in order to maintain safe home care and adequate working conditions. These were: day-by-day learning (on-the-job practice, self-learning and collegial learning); balancing relations with the patient (sufficiently close, yet sufficiently distant); self-managing (via informal leadership and peer-support); and navigating the patient care system (by coordinating patient care and being one step ahead).

Keeling (2014) contends that technology has a crucial role to play in optimising the advantages of home care and in so doing meet the oncoming challenges of an ageing population. For instance, Bossen et al (2013) investigated the nature of cooperative work between relatives and home care workers around elderly persons in Denmark. They found that home care work is highly cooperative in nature and involves substantial coordinative efforts on the part of the actors involved. They also believe that this cooperative relationship can be facilitated and augmented by information and communications technology. They have developed a prototype system for this pupose, called CareCoor.

The challenge of retention of home care workers from their own perspective was explored by Fleming and Taylor (2006). They undertook a cross-sectional survey

Home care workers also commented on negative client attitudes and feeling taken for granted by some service users and their families

using a convenience sample in which questionnaires were completed by 45 healthcare workers in Northern Ireland. In addition, focus groups with 12 healthcare workers were undertaken to explore emerging themes. Amongst other data, healthcare workers provided reasons for considering leaving their jobs. These included irregular, unsuitable and unsociable hours. Workload pressures were also highlighted, with 60% of respondents noting that they 'sometimes' or 'never' had enough time to carry out all of their work. Home care workers also commented on negative client attitudes and feeling taken for granted by some service users and their families.

More recent work has also examined the retention of home care workers. Butler et al (2014) undertook a mixed-method study that explored the determinants of longer job tenure for home care aides (n=261) in the USA. Study participants were followed for 18 months, each completing two mail surveys and one telephone interview during that time. Predictors of longer job tenure included older age, living rurally, lower physical function, higher wages, a greater sense of autonomy on the job, and less frequent feelings of personal accomplishment. Thematic analysis of telephone interviews revealed long-term stayers to be less concerned about low wages and inconsistent hours than those who left their jobs within a year.

Banijamali et al (2014) surveyed former home care workers in the US, comparing 'leavers' to current home care workers. They found that those who had left the profession were more highly educated, had higher household income, and were more likely to be white. Amongst 'leavers', those who were newly employed had better benefits, wages, hours and career mobility than in their home care jobs. It was concluded that the low status and poor pay of home care workers may result in the inability of the profession to retain those who face better prospects.

## Specific experiences in end-of-life care

There exist a limited number of studies that examine the relationships between family carers and home care support workers within the specific context of palliative care. In 2009, Devlin and McIlfatrick published an extensive literature review and found that this particular field is understudied, with research tending to focus on provision of palliative care by community nurses (Austin et al, 2000; Dunne et al, 2005; Hughes, 2004; McKenzie et al, 2007). They argued that *"... since home care workers work at the coalface of service provision alongside community nurses, their needs and role are equally worthy of investigation ... [and] ... there is some confusion around the role of the home care worker, both from a health professional and patient/carer perspective, it is important that a clearer definition of the home care worker's role in palliative and end-of-life care is developed."* (p. 531).

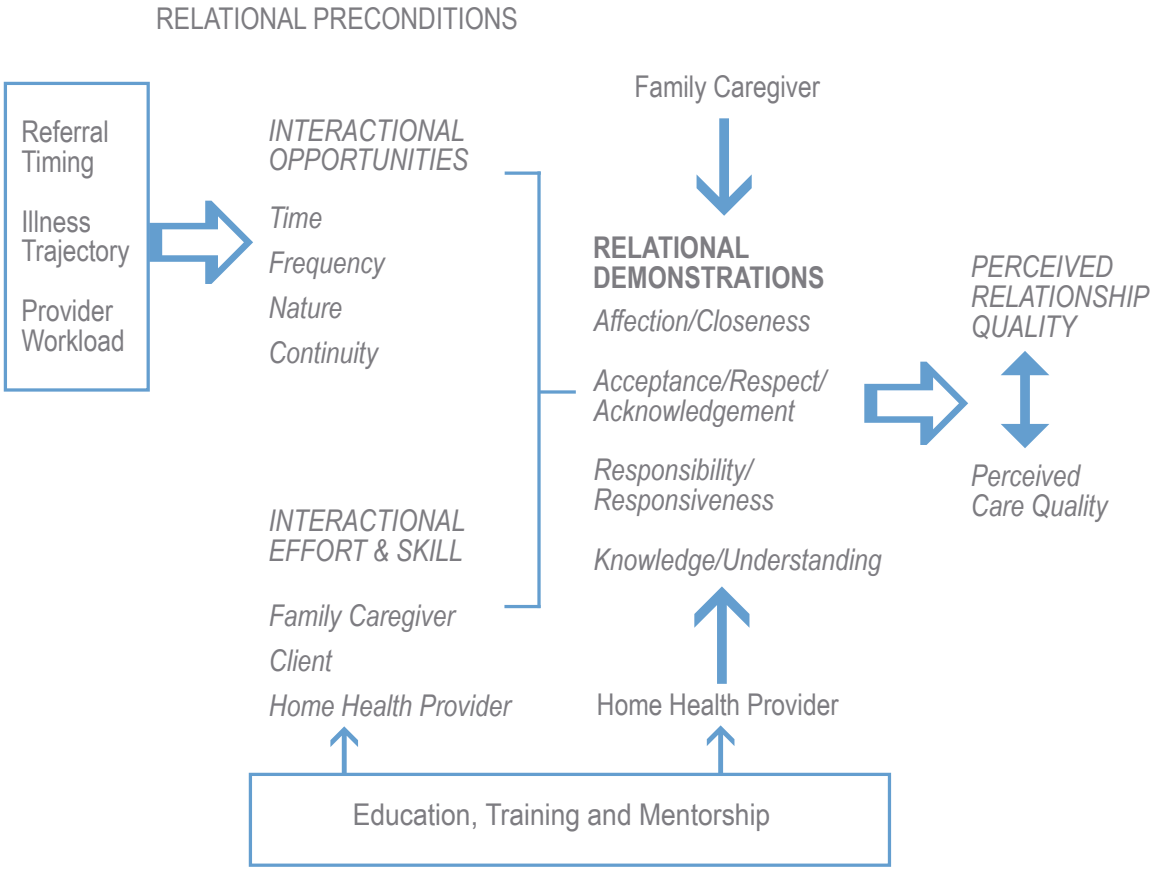
Herber (2013) undertook a systematic literature review of articles relating to the role of healthcare support workers in providing palliative and end-of-life care in the community. He found that home care support workers offer domestic support and provide an important source of respite for family members. However, a number of challenges for healthcare support workers were also identified. These included inadequate training and attachment to the dying person as a potential source of stress (Denham et al 2006; Schell & Kayser-Jones, 2007). Research by Boerner et al (2014) found that grief symptoms like those experienced by family caregivers are common amongst direct care workers after patient death. They conducted a cross-sectional study of certified nursing assistants (n=140) and home care workers (n=80) who had recently experienced patient death. Data analysis of standardised assessments and structured questions found that their reactions reflected many of the core grief symptoms reported by bereaved family caregivers. For instance, feelings of being 'not at all prepared' for the death and struggling with 'acceptance of death' were prevalent amongst staff. That concluded that increasing preparedness for this experience through better training and support is likely to improve the occupational experience of direct care workers and ultimately allow them to provide better palliative care.

grief symptoms like those experienced by family caregivers are common amongst direct care workers after patient death

Funk and Stajduhar (2013) explored family caregivers' accounts of the nature and quality of their relationships with home care nurses, when caring for a dying person at home. Ethnographic, qualitative interviews were conducted with bereaved caregivers (n=26) in one Western Canadian regional health agency. Data analysis was informed by symbolic interactionism. Study participants described their relationships with home care nurses and spoke about

their assessments of the care provided. Findings highlighted the importance of the length, frequency and continuity of contact, conversation, socialising and information sharing. Participants were cognisant of their own and care recipients' roles in building relationships. Nurse behaviours demonstrating affection, acknowledgement, commitment, and understanding were appreciated by the caregivers. Drawing on the data gathered in this study, they developed a model (Figure 4) with the potential to act as *"... an illustrative guide to help policy makers and practitioners understand family caregivers' perceptions of relationship and care quality, and identify potential areas for targeted practice intervention and health service improvement"* (p. 200). They point out that this could lead to, for instance, system changes enhancing nurse continuity with families, or facilitating their ability to deliver appropriate levels of support that enhance families' sense of comfort. They believe that such practice interventions would focus on education, training and mentorship directed to the development of interactional skill and relational behaviours. However, they also note that the model is general, in that a 'good' relationship varies to some extent between family caregivers (for example, regarding sharing of personal information), highlighting the need for individualisation in practice.

**Figure 4: Model of family caregivers' relationships with home health providers and perceptions of the quality of formal services (Funk & Stajduhar, 2013)**



Horsfall et al (2013) undertook a qualitative study in Australia to develop an understanding of how formal and informal carers work together when care is being provided in a dying person's home. They were interested in formal providers' perceptions and knowledge of informal networks of care and identifying barriers to the networks working together. In so doing, the authors explored the nature of the relationship between formal and informal networks and the potential for strengthening that relationship. Ten focus groups were conducted in urban, regional and rural Australia, comprising 88 participants. It was shown that formal providers are aware and supportive of the vital role informal networks play in the care of the dying at home. However, a number of barriers to formal and informal networks working together more effectively were identified, with the strongest being the complex rules and regulations that participants were operating in, including those relating to risk management, privacy and confidentiality. They found that the stated Australian policy of health-promoting palliative care is not substantially translating in practice.

Ventura et al (2013) undertook a systematic literature review on the unmet needs of palliative home care patients and carers. They found that coordination and communication problems within services led to uncertainty for both patients and carers as to who should be contacted in times of need. Different healthcare staff may therefore attend patients' homes, leading to poor continuity of care. As a result, health workers are often not aware of the services delivered by other professionals, and both patients and carers have difficulty in forming relationships with service workers.

Percival et al (2013) undertook an explorative study of the domiciliary care worker role in meeting the needs of families caring for those dying at home in England. They conducted qualitative formal interviews with family members (n=42), staff (n=6) and a patient (n=1), as well as observation sessions and informal interviews with additional family caregivers and staff, to examine the aspects of domiciliary care perceived to be of most value. They compared and contrasted family caregivers' experiences of the support provided by generic domiciliary care workers with that of a team of specialist domiciliary care workers. Findings showed that specialist domiciliary care workers had sufficient time and expertise to meet family caregivers' physical and emotional needs in sensitive, proactive and family-centred ways. However, these attributes were not so prominent in the services received from generic domiciliary care workers. They concluded that the availability to families of targeted support from an appropriately trained and carefully monitored team of specialist domiciliary care workers, able to operate flexibly and with staff consistency, appears to be an important foundation on which to build greater confidence in the reality of a good death at home.

## The role of migrant home care support workers

Whilst migrant home care support workers have received considerable attention within the literature, it is not within the specific remit of this review. It is nonetheless important that the role of migrant workers, as major providers of home care, is acknowledged.

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According to the Organisation for Economic Cooperation and Development (OECD, 2012), foreign workers employed in the healthcare sector comprised 3-24.3% of all foreign workers in Western developed countries in 2011. The European FUTURAGE project, through extensive stakeholder consultation, identified the phenomenon of migrant care workers as one of the main priorities for ageing research in the next 10-15 years (Chiatti et al, 2011). In particular, the extensive use of both live-in and live-out migrant care workers, whose status lies between the two distinct categories of formal and informal carers, is a relatively new trend in long-term care provision (Triantafillou et al, 2010).

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Manthorpe et al (2012) undertook a large study of international recruitment to the English social care sector. They sought to understand what led to satisfaction of care and what led to preference and satisfaction with workers. Data was collected from face-to-face interviews with 35 people who were using social care services and carers. Using the theoretical concept of homophily, they explored the contention that people might prefer to receive care and support from individuals resembling themselves. They observed that while preferences for care workers and satisfaction with social care services may be linked, meeting a preference is personal to the individual.

Migrant care workers are generally regarded as committed, compassionate and loyal (Martin et al, 2009; Spencer et al 2010). Chiatti et al (2013) assessed the impact of privately employed migrant care workers on the burden of Italian family members who care for a disabled older person. Some 990 family caregivers were enrolled in their study and successful follow-ups were completed with 863 subjects. The surveys also

assessed the level of caregiver burden. The authors found that, following a one-year follow-up, family carers employing a migrant care worker were significantly protected against burden increase, whilst those who could not rely on the support of other family members were exposed to the risk of burden increase. Other formal services were found to not have any protective effect.

Walsh and Shutes (2013) explored the relationship between older people and migrant workers in a range of jobs both in Ireland and the UK. Their study drew on data collected in both countries between 2007 and 2010, including focus groups with older people (n=41), interviews with migrant care workers (n=90) and a survey of, and interviews with, employers. Whilst predominantly positive, care relationships emerged as complex multifaceted constructions that were need-orientated, friendship- and familial-like, reciprocal and discriminatory. The majority of migrant workers described relationships with older care recipients that went beyond service provider and service user. They spoke about a closeness and a personal attachment to the people they cared for; labels of 'sons' and 'daughters' were frequently used by both migrant care workers and older people to illustrate the strength of the relations between caregivers and care users. Significantly, the study also identified factors that shaped the development of a care relationship between migrant care workers and older people and which could sometimes pose challenges. These included history, language and customs around care approaches. Some employers felt that communication difficulties and not having a shared cultural outlook could hinder the development of a strong care relationship. Coupled with the challenges of working in a demanding and schedule-driven environment, these have the potential to undermine the focus on the older person.

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The Migrant Rights Centre Ireland (MRCI, 2012) undertook a needs analysis of the situation of migrant care workers undertaking care work with older persons in private homes and private residential care settings in Ireland. As part of this research, they engaged with over 115 migrant care workers using a community development and empowerment approach. Eight migrant care workers were facilitated to act as peer researchers to the project who carried out 80 surveys across the country with migrant care workers. Two focus groups were also conducted targeting 27 migrant care workers. In addition, four case studies were carried out to examine in-depth the experience of migrant care workers in different care settings. Participants reported being consistently required to do extra tasks not specified in their contracts or that

workers feeling their abilities where constantly being questioned despite long years of service to directly racist comments based on their nationality

exceeded their role of care worker (for example, undertaking laundry in the nursing home environment, car washing, running errands, emptying bins, care of animals, general cleaning – such as cleaning windows and family rooms – and kitchen duties not related to the care of the client – such as heavy duty cleaning of ovens). Significantly, more than half did not feel valued and respected by their employers. Over 40% of participants said that they felt discriminated against by their employers. This ranged from workers feeling their abilities where constantly being questioned despite long years of service to directly racist comments based on their nationality. The majority of those surveyed indicated that discrimination was part of their daily working life, that they felt had to be borne as Ireland is not their home country.

In 2009, a number of large-scale studies exploring the role of migrant care workers in ageing societies, and their impact on the quality of healthcare, were published in Canada (Bourgeault et al), Ireland (Walsh & O'Shea), the UK (Cangiano et al) and the US (Martin et al). The combined results are discussed in an International Organisation for Migration report (Spencer et al, 2010). One of the key findings across the studies, was that the issues faced by migrant care workers need to be framed within the broader marginalisation of the older adult care sector as a whole. These include the long-standing issues of low status (see Smith and Mackintosh, 2007, for an analysis of the longstanding stigma attached to older adult care), lack of prioritisation, lack of funding, lack of training, and lack of career development for carers. Some would argue that these are the same sort of macro-sector issues that are likely to frame the relationship between formal and informal carers (personal communication from Dr. Kieran Walsh, Irish Centre for Social Gerontology, National University of Ireland Galway).

The familial-like relationships that often develop in these contexts is not always a positive attribution and instead turns into a situation where expectations are placed on the workers that go beyond those of a professional paid service

Ho and Chiang (2014) comment on the existence of structural inequalities based on race and gender among the migrant care workers' workforce. Related issues include the working conditions of migrant care workers, the relationships of care between migrant care workers and care-recipients, and the quality of care. The familial-like relationships that often develop in these contexts is not always a positive attribution and instead turns into a situation where expectations are placed on the workers that go beyond those of a professional paid service.

Exploitation of migrant care workers is receiving growing attention internationally. Anderson and O'Connell-Davison (2003) conducted research on employer demand for domestic workers in private households in selected European and Asian countries. Through interviews with employers, they found that migrant workers were valued because of their vulnerability and lack of choice, as it was believed they were less likely to quit without notice, either because of their immigration status or because they had nowhere else to go. The interviewees constructed domestic work as involving a relationship of mutual dependence, in which the impoverished domestic worker needs money/work and the employer needs a 'flexible' worker.

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In Canada, Cummings et al (2013) conducted a needs assessment study to describe the complexity of Alberta's healthcare aide workforce and recommend approaches to address knowledge gaps in workforce planning. They found that healthcare assistants were an invisible component in the multidisciplinary healthcare workforce, primarily because they are unregulated. The image of healthcare assistants' work is negative and there is an increasing expectation that they will work autonomously providing direct patient care. In contrast to this, Di-Santo and Ceruzzi (2010) in Italy, found that increasing opportunities were being provided for migrant workers upgrading to the level of semi-professionals, through training and regularisation of their work status.

## Conclusions

Internationally, encouraging strides have been made in recent years in terms of gaining an understanding of the relationship between family carers and home care support workers. Unfortunately, no work directly exploring this issue has been conducted in Ireland. Only two pieces of Irish research were identified in the course of this literature review, and these were only partially relevant, as they looked at the issue of migrant care workers in a broader context (MRCI, 2012; Walsh & Shutes, 2013). Promising research was, however, conducted in Northern Ireland on factors influencing home care worker retention (Fleming & Taylor, 2006). The bulk of the work completed in this field is in fact from Canada.

Although the international experience is useful, direct comparisons with Ireland are problematic due to differing healthcare systems, as well as differences in the wider policy and societal context

Findings from this review must be approached with a certain level of caution. Although the international experience is useful, direct comparisons with Ireland are problematic due to differing healthcare systems, as well as differences in the wider policy and societal context. In addition, the majority of the research in this area is qualitative in nature. Qualitative research provides important in-depth information on participants' perceptions and experiences. However, in the absence of large scale quantitative data, it is arguably difficult to generalise findings. Furthermore, fundamental problems exist in terms of how 'relationships' between family carers and home care support have been defined within the research.

It is acknowledged that no distinct consideration has been given in this review to the personal relationships existing in the provision of independent living services for those with (generally) lifelong physical and sensory disabilities. The focus instead has been more on traditional home care supports that are provided, by and large, to over 65-year olds who tend to require supports with ADLs/IADLs on a more incremental basis. The quantum of support provided to this older group is likely to be considerably larger than the support provided to enable people with disabilities to live independent lives. The ageing cohort of the population is likely to have significantly higher levels of family carer involvement than younger age groups with disibilities, for whom, in keeping with the objectives of the independent living movement, there is less direct family involvement in supporting them to live independently. Additionally, it is recognised that the language of 'care' does not fit comfortably within this context. The independent living movement avoids the use of this term, preferring to describe the supports needed

as ‘personal assistance’ and the like. This is an important distinction and speaks rightly to challenge the medical model of disability and the potential for ‘care’ to limit the enablement of individuals. The work of the Disability Federation of Ireland, who, with the assistance of the Irish Wheelchair Association and the Center for Independent Living, recently undertook an examination of personal assistant services in Ireland should be noted here (Buchanan, 2014).

There is a growing body of research that challenges the traditional client-centred approach to home care. The literature has begun to recognise this, and there is an increasing promotion of a partnership approach to home care, recognising that care relationships include clients, family carers and home care support workers. The roles of family carers and home care workers are multi-faceted, inextricably interconnected and the boundaries between each are fuzzy at times. Factors have been identified that promote positive relationships, as well as barriers that work against such positive relationships. Reflecting on the literature, there may be significant merit in thinking about challenges as those that stem from the didadic/triadic care relationship itself, those that are related to the care needs/dependency level of the older person, those that stem for the organisation environment, and those that stem from a broader macro-environment that by necessity seeks to limit and allocate resources on a crude time basis.

One specific opportunity that warrants mention is the use of information and communications technology as an aid for both family carers and home care support workers, with the potential to have a positive impact on their relationship

One specific opportunity that warrants mention is the use of information and communications technology as an aid for both family carers and home care support workers, with the potential to have a positive impact on their relationship. Whilst not specifically discussed in this review, the value of carer assessments as a means to enhance the relationship between family carers and home care support workers is nonetheless important. The imminent introduction in Ireland of a Single Assessment Tool by the Health Service Executive to identify care needs (initially of those aged 65+), will act as a gateway to an appropriate use of a new Carer Needs Assessment, developed in collaboration with InterRAI (Care Alliance Ireland, 2013c). This leaves open the possibility for home care support workers’ interventions to be more aligned to the expressed needs of not only the primary client but also of the family carer, and for such carers to be seen as partners in care, in keeping with the National Carers’ Strategy.

Gaining a deeper understanding of both the positive and negative aspects of the relationship can help to target quality improvement initiatives for individuals in receipt of care, family carers and home care support workers

What are the potential benefits of conducting further primary research exploring the complex relationship dynamics between family carers and home care support workers? There can be no doubt that evidence-based research on this topic has the potential to have a positive impact on number of fronts, especially if it results in Ireland-specific data. In comparison with other health and social care provisions (residential, acute, disability), home-based elder care appears to have a particularly low status and level of remuneration. This serves to limit the pool of available people to provide this type of care and creates challenges to the delivery of consistently high levels of care. Home-based care, by its very nature, operates in the privacy of people's homes and in Ireland, at any rate, remains unregulated. Gaining a deeper understanding of both the positive and negative aspects of the relationship can help to target quality improvement initiatives for individuals in receipt of care, family carers and home care support workers. High quality research evidence is also crucial in the development of policies, particularly in an era of budget constraints and cutbacks in support services. It can be used to guide the making of informed decisions and the allocation of limited resources. Such decisions need to be flexible and tailored to individual needs; there is no one-size-fits-all solution. Finally, research findings are crucial to the provision of adequate education and training for all key stakeholders within the home care sector: family carers; home care support workers; policy makers and administrative staff.

In conclusion, this literature review has shown that the the roles of family carers and home care support workers are undeniably interlinked and that the two systems of care need to be planned not alongside each other but together. It is vital that family carers and home care workers are recognised as partners in the provision of care in the home and are adequately supported to perform their unique roles.

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# References


Adams, T. & C.L. Clarke (eds.) (1999). *Dementia Care: Developing partnerships in practice.* London: Balliere Tindall.

Anderson, B. & O'Connell-Davison, J. (2003) *Is trafficking in human beings demand driven? A multi-country pilot study*. Geneva: International Organisation for Migration.

Attree, M. (2001) Patients' and relatives' experiences and perspectives of 'good' and 'not so good' quality care. *Journal of Advanced Nursing,* 33: 456-466.

Austin, L. et al (2000) Palliative care: community nurses' perceptions of quality. *International Journal for Quality in Health Care* 9 (3): 151-158.

Banijamali, S. et al (2014) Characteristics of home care workers who leave their jobs: A cross-sectional study of job satisfaction and turnover in Washington State. *Home Healthcare Services Quarterly,* 33 (3): 137-158.

Barrett, A. et al (eds.) (2011) *Fifty Plus in Ireland: First results from The Irish Longitudinal Study on Ageing. Dublin: TILDA.*

Barrett, A. & Rust, A. (2009) *Projecting the Future Numbers of Migrant Workers in the Health and Social Care Sectors in Ireland.* Working Paper 275. Dublin: Economic and Social Research Institute.

Boerner, K. et al (2014) Grief after patient death: direct care staff in nursing homes and home care. *Journal of Pain and Symptom Management,* early view online issue.

Bossen, C. et al (2013) CareCoor: augmenting the coordination of cooperative home care work. *International Journal of Medical Informatics*, 82: E189-E199.

Bourgeault, I. et al (2009) *The Role of Immigrant Care Workers in an Ageing Society: The Canadian context and experience*. Ontario: University of Ottowa.

Brereton, L. & Nolan, M. (2003) Seeking Partnerships between Family and Professional Carers: Stroke as a case in point. In: Nolan, M. et al. *Partnerships in Family Care: Understanding the caregiving career*. Buckingham & Philadelphia: Open University Press.

Buchanan, L. (2014) *Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities*. Dublin: Disability Federation of Ireland.

Büscher, A. et al (2011) Negotiations about helpfulness – the relationship between formal and informal care in home care arrangements. *Scandinavian Journal of Caring Studies*, 25: 706-715.

Butler, S. S. (2013) Older women doing home care: exploitation or ideal job? *Journal of Gerontological Social Work*, 56 (4): 299-317.

Butler, S. S. et al (2014) Determinants of longer job tenure among home care aides: What makes some stay on the job while others leave? *Journal of Applied Gerontology*, 33 (2): 164-188.

Byrne, K. et al (2011) 'I'm satisfied ... but': clients and families contingent responses about home care. *Home Healthcare Services Quarterly*, 30 (4): 161-177.

Byrne, K. et al (2012) Valuing the older person in the context of delivery and receipt of home support: client perspectives. *Journal of Applied Gerontology*, 31: 377-401.

Cahill, S. E. et al (2012) *Creating excellence in dementia care: A research review for Ireland's National Dementia Strategy*. Dublin: School of Social Work and Social Policy, Trinity College Dublin & Galway: Irish Centre for Social Gerontology.

Cangiano, I. et al (2009) *Migrant Care Workers in Ageing Societies: Research findings in the United Kingdom*. Oxford: University of Oxford.

CARDI (2011) *CARDI Focus on Models of Care*. Belfast/Dublin: CARDI.

Care Alliance Ireland (2008) *Health and Wellbeing of Family Carers in Ireland: Results of a survey of recipients of the Carer's Allowance*. Dublin: Care Alliance Ireland.

Care Alliance Ireland (2012) *Pre-Budget Submission 2013 to the Department for Social Protection*. Dublin: Care Alliance Ireland.

Care Alliance Ireland (2013a) *Family Caring in Ireland.* Dublin: Care Alliance Ireland.

Care Alliance Ireland (2013b) *Pre-Budget Submission for Budget 2014 to the Department for Social Protection*. Dublin: Care Alliance Ireland.

Care Alliance Ireland (2013c) *The Case for Carer Assessments*. Dublin: Care Alliance Ireland.

Carers' Strategy Consultation Group (2008) *Submission to the National Carers' Strategy Process.*

Caron, C. D. et al. (2005) Decision making at the end of life in dementia: How family caregivers perceive their interactions with health care providers in long-term-care settings. *Journal of Applied Gerontology*, 24: 231-247.

Chiatti, C. et al (2011) Guaranteeing the quality and sustainability of social protection systems. In Walker, A. (ed.) *FUTURAGE: A Road Map for European Ageing Research* (pp. 50-57).

Chiatti, C. et al (2013) Migrant care workers as protective factor against caregiver burden: results from a longitudinal analysis of the EUROFAMCARE study in Italy. *Aging and Mental Health*, 17 (5): 609-614.

Clark, C. A. et al (1995) An exploratory study of how occupational therapists develop therapeutic relationships with family caregivers. *American Journal of Occupational Therapy*, 49 (7): 587-594.

Clarke, C. L. (1999) Dementia care partnerships: knowledge, ownership and exchange. In Adams, T. & Clarke, C. L. (eds.) *Dementia Care: Developing partnerships in practice.* London: Balliere Tindall.

CSO (2007) *Census 2006 – Volume 11: Disability, Carers and Voluntary Activities*. Dublin: Stationary Office.

CSO (2012) *Census 2011 – Profile 8 – Our Bill of Health*. Dublin: Stationary Office.

Cummings, G. C. et al (2013) *Shining a Light on the Unregulated Health Aide Workforce: Final report.* Edmonton: Faculty of Nursing, University of Alberta.

Denham, S. A. et al (2006) Knowledge of rural nurses' aides about end-of-life care. *Family and Community Health*, 29: 229-241.

Department of Health (2011a) *Comprehensive Review of Expenditure.* Dublin: Department of Health.

Department of Health (2011b) *Long Stay Activity Statistics 2010.* Dublin: Department of Health.

Department of Health (2012) *The National Carers' Strategy: Recognised, Supported, Empowered*, Dublin: Department of Health.

Department of Health (2013) *The National Carers' Strategy: First Annual Progress Report*. Dublin: Department of Health.

Devlin, M. & McIlfatrick, S. (2009) The role of the home care worker in palliative and end-of-life care in the community setting: a literature review. *International Journal of Palliative Nursing*, 15 (11): 526-532.

Dewar, B. & Nolan, M. (2013) Caring about Caring: Developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*, 50: 1247-1258.

Di-Santo, P. & Ceruzzi, F. (2010) *Case Study on Migrant Care Workers in Italy*. (unpublished Interlinks working paper).

Duncan, P. (2011) Concern over slow progress in regulating home helps. *Irish Times*, 15 December.

Duncan, M. T. & Morgan, D. L. (1994). Sharing the caring: family caregivers' views of their relationships with nursing home staff. *Gerontologist*, 34 (2): 235-244.

Dunne, K. et al (2005) Palliative care for patients with cancer: district nurses' experiences. *Journal of Advanced Nursing,* 50 (4): 372-80.

England, K. & Dyck, I. (2011) Managing the body work of home care. *Sociology of Health and Illness*, 33 (2): 206-219.

Fischer, L.R. & Eustis, N. N. (1994). Care at home: family caregivers and home care workers. In Kahana, E. et al. Family Caregiving Across the Lifespan. Thousand Oaks, California: Sage.

Fleming, G. & Taylor, B. J. (2006) Battle on the home care front: perceptions of home care workers on factors influencing staff retention in Northern Ireland. *Health and Social Care in the Community*, 15 (1): 67-76.

Friedemann, M. L. et al (1997) Family involvement in the nursing home: family-oriented practices and staff-family relationships. *Research in Nursing and Health*, 20: 527-537.

Funk, L. M. et al (2009). Palliative family caregivers' accounts of health care experiences: the importance of 'security'. *Palliative and Supportive Care*, 7: 435-447.

Funk, L. & Stajduhar, K. (2013) Analysis and proposed model of family caregivers' relationship with home health providers and perceptions of the quality of formal services, *Journal of Applied Gerontology*, 32: 188-206.

Gantert, T. W. et al (2008) The key to me: seniors' perceptions of relationship-building with in-home service providers. *Canadian Journal on Aging*, 27: 23-34.

Gantert, T. W. et al (2009) Working it out together: family caregivers perceptions of relationship-building with in-home service providers. *Canadian Journal of Nursing Research*, 41 (3): 44-63.

Genet, N. et al (2013) *Home care across Europe: Case studies.* Geneva: Observatory on Health Systems and Policies, World Health Organisation.

Gilmour, J. A. (2002). Dis/integrated care: family caregivers and in-hospital respite care. *Journal of Advanced Nursing*, 39 (6): 546-553.

Gladstone, J. & Wexler, E. (2002) Exploring the relationships between families and staff caring for residents in long-term care facilities: family members' perspectives. *Canadian Journal on Aging*, 21: 39-53.

Goldschmidt, D. et al (2006) Expectations to and evaluation of a palliative home-care team as seen by patients and carers. *Supportive Care in Cancer*, 14: 1232-1240.

Guberman, N. et al (2006) Formal service practitioners' views of family caregivers' responsibilities and difficulties. *Canadian Journal of Aging*, 25 (1): 43-53.

Hasselkus, B. (1988) Meaning in family caregiving: perspectives on caregiver/professional relationships. *Gerontologist*, 28: 686-691.

Herber, O. R. (2013) The role of healthcare support workers in providing palliative and end-of-life care in the community: a systematic literature review. *Health and Social Care in the Community*, 21 (3): 225-235.

Hertzberg, A. & Ekman, S. (2000). 'We, not them and us?' Views on the relationships and interactions between staff and relatives of older people permanently living in nursing homes. *Journal of Advanced Nursing,* 31 (3): 614-622.

Ho, K. H. M. & Chiang, V. C. L. (2014) A meta-ethnography of the acculturation and socialization experiences of migrant care workers. *Journal of Advanced Nursing*, early view online issue.

Horsfall, D. et al (2013) Working together-apart: exploring the relationship between formal and informal care networks for people dying at home. *Progress in Palliative Care*, 21 (6): 331-336.

HSE (2010) *National Guidelines and Procedures for Standardised Implementation of the Home Care Packages Scheme*. Dublin: HSE.

HSE (2012) *HSE: Annual Report and Financial Statements 2011*. Dublin: HSE.

HSE (2013) 2014 *HSE Service Plan*. Dublin: HSE.

Hughes, L. (2004) Palliative care in the community. *Primary Health Care*, 14 (6): 27-31.

Hupcey, J. E. (1998) Establishing the nurse-family relationship in the intensive care unit. *Western Journal of Nursing Research*, 20: 180-194.

Keeling, D. I. (2014) Home care user needs from the perspective of the patient and carers: a review. *Smart Home Care Technology and Telehealth*, 2, 63-76.

Laitinen, P. & Isola, A. (1996) Promoting participation of informal caregivers in the hospital care of the elderly patient: informal caregivers' perceptions. *Journal of Advanced Nursing*, 23 (5): 942-947.

Lang, A. et al (2013) Researching triads in home care: perceptions of safety from home care clients, their caregivers and providers. *Home Healthcare Management and Practice*, early view online issue.

Law Reform Commission (2012) *Legal Aspects of Professional Home Care*. Dublin: Law Reform Commission.

Lundström, F. & McKeown, F. (1994) *Home Help Services for Elderly People in Ireland*. Dublin: National Council for the Elderly.

Lynn-McHale, D. J. & Deatrick, J. A. (2000) Trust between family and health care provider. *Journal of Family Nursing*, 6: 210-230.

Lyons K. S. & Zarit S. H. (1999) Formal and informal support: the great divide. *International Journal of Geriatric Psychiatry*, 14: 183-196.

Manthorpe, J. et al (2012) User and carer experiences of international social care workers in England: listening to their accounts of choice and control. *Australian Social Work*, 65 (4): 442-456.

Martin, S. et al (2009) *The Role of Migrant Care Workers in Ageing Societies: Report on research findings in the United States*. Washington DC: Institute for the Study of International Migration, Georgetown University.

McGill, P. (2010) *Illustrating Aging in Ireland North and South: Key facts and figures*. Belfast/Dublin: CARDI.

McKenzie, H. et al (2007) A sense of security for cancer patients at home: the role of community nurses. *Health and Social Care in the Community*, 15 (4): 352-359.

McPherson, K. M. et al (2014) Improving the interface between informal carers and formal health and social services: a qualitative study, *International Journal of Nursing Studies,* 51 (3): 418-429.

McWilliam, C. L. et al (2001) The experience of empowerment in in-home services delivery. *Home Health Care Services Quarterly*, 20 (4): 49-71.

Milberg, A. & Strang, P. (2007) What to do when 'there is nothing more to do?' A study within a salutogenic framework of family members' experience of palliative home care staff. *Psycho-Oncology*, 16, 741-751

Morss Dy, S. et al (2008) A systematic review of satisfaction with care at the end of life. Journal of the American Geriatrics Society, 56: 124-129.

MRCI (2012) *Who Cares? The experience of migrant care workers in Ireland*. Dublin: MRCI.

Murray, E. K. et al (2013) *Access to Specialist Palliative Care Services and Place of Death in Ireland: What the data tells us*. Dublin: Irish Hospice Foundation.

Murphy, C. (2012) Evidence from the first wave of The Irish Longitudinal Study on Ageing [Chapter 5 Appendix]. In Wren, M. et al. *Towards the Development of a Predictive Model of Long-Term Care Demand for Northern Ireland and the* Republic of Ireland. Dublin: Centre for Health Policy and Management, Trinity College Dublin.

Murphy, C. & Turner, T. (2014) Organising non-standard workers: union recruitment in the Irish care sector. *Industrial Relations Journal,* early view online issue.

NESC (2012) *Quality and Standards in Human Services in Ireland: Home care for older people*. Dublin: NESC.

NESF (2009) *Implementation of the Home Care Package Scheme*. Dublin: NESF.

Nolan, M. & Dellasega, C. (1999) 'It's not the same as him being at home': creating caring partnerships following nursing home placement. *Journal of Clinical Nursing*, 8: 723-730.

Nolan, M. et al. (2004). Beyond person centred care: A new vision for gerontological nursing. , 13 (3a): 45-53.

OECD (2012) *International Migration Outlook 2012*. OECD Publishing.

Öhlén J. et al (2007) Relatives in end-of-life care – part 2: A theory for enabling safety. Journal of Clinical Nursing, 16: 382-390.

PA Consulting Group (2009) *Evaluation of Home Care Packages*. Dublin: Stationary Office.

Patmore C. (2002) *Towards Flexible, Person-Centred Home Care Services*. York: Social Policy Research Unit, University of York.

Patmore, C. & McNulty, A. (2005) *Flexible, Person-Centred Home Care for Older People*. York: Social Policy Research Unit, University of York.

Penning, M. J. & Keating, N. L. (2000) Self, informal and formal care: Partnerships in community-based and residential care settings. **Canadian Journal on Aging**, 19 (Suppl.): 75-100.

Percival, J. et al (2013) 'Earthly Angels?' a qualitative study of the domiciliary care worker role in meeting the needs of families caring for those dying at home. *Palliative and Supportive Care*: 1-9.

Piercy K. W. (2000) When it is more than a job: close relationships between home health aides and older clients. *Journal of Aging and Health*, 12 (3): 362-387.

Piercy, K. W. & Dunkley, G. J. (2004) What quality paid home care means to family caregivers, *Journal of Applied Gerontology*, 23: 175-192.

Piercy, K. W. & Wooley, D. N. (1999) Negotiating worker-client relationships: a necessary step to providing quality home health care. *Home Health Care Services Quarterly*, 18: 1-24.

Post, S.G. (2001) Quality of life and quantity of lives in dementia care: review essay. *Gerontologist*, 41 (1): 139-140.

Qureshi, H. et al (2000) *Outcomes in Social Care Practice: Developing an outcome focus in care management and use surveys*. York: Social Policy Research Unit, University of York.

Russell, D. et al (2013) Continuity in the provider of home health aide services and the likelihood of patient improvement in activities of daily living, *Home Healthcare Management and Practice*, 25 (1): 6-12.

Ryan, T. et al (2004) 'Part of the family:' sources of job satisfaction among a group of community-based dementia care workers, *Health and Social Care in the Community*, 12 (2): 111-118.

Scharer, K. (1999). Nurse-parent relationship-building in child psychiatric units. *Journal of Child and Adolescent Psychiatric Nursing*, 12 (4): 153-170.

Schell, E. S. & Kayser-Jones, J. (2007) 'Getting into my skin': empathy and role taking in certified nursing assistants' care of dying residents. *Applied Nursing Research*, 20: 146-151.

Sims-Gould, J. et al (2013) Worker's experiences of crisis in the delivery of home support services to older clients: a qualitative study, *Journal of Applied Gerontology,* 32 (1): 31-50.

Sims-Gould, J. & Martin-Matthews, A. (2010a) Strategies used by home support workers in the delivery of care to elderly clients, *Canadian Journal of Aging*, 29 (1): 97-107.

Sims-Gould, J. & Martin-Matthews. A. (2010b) We share the care: family caregivers' experiences of their older relative receiving home support services, *Health and Social Care in the Community*, 18 (4): 415-423.

Smith, P. & Mackintosh, M. (2007) 'Profession, market and class: nurse migration and the remaking of division and disadvantage', *Journal of Clinical Nursing* , 16 (12): 2213-2220.

Soodeen, R. A. et al (2007) Home care for older couples: 'It feels like a security blanket ...' *Qualitative Health Research,* 17: 1245-1255.

Spencer, S. et al (2010) *The Role of Migrant Care Workers In Ageing Societies: Report on research findings in the United Kingdom, Ireland, Canada and the United States.* Geneva: International Organisation for Migration.

Steinhauser, K. E. et al (2000) Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association*, 284: 2476-2482.

Stone R. I. & Dawson, S. L. (2008) The origins of better jobs better care. *Gerontologist*, 48 (1): 5-13.

Swartz, A. N. & Vogel, M. E. (1990) Nursing home staff and residents' families role expectations. *Gerontologist,* 30 (1): 49-53.

Swedberg, L. et al (2013) From risky to safer home care: Healthcare assistants striving to overcome a lack of training, supervision and support, *International Journal of Qualitative Studies on Health and Well-being*, 8: 20758.

Tarricone, R. & Tsouros, A. (2008) *The Solid Facts: Home care in Europe*. World Health Organisation.

Thorne, S. E. & Robinson, C. A. (1989) Guarded alliance: Health care relationships in chronic illness. *IMAGE: Journal of Nursing Scholarship*, 21: 153-157.

Timonen, V. & Doyle, M. (2007a) *Home Care for Ageing Populations: a comparative analysis of domiciliary care in Denmark, the United States and Germany*. Cheltenham: Edward Elgar.

Timonen, V. & Doyle, M. (2007b) Worlds Apart? Public, private and non-profit sector providers of domiciliary care for older persons in Ireland. *Journal of Aging Studies*, 21 (3): 255-265.

Timonen, V. et al (2011) Home Care in Ireland. In Rostgaard, T. et al (eds.), *LIVINDHOME: Living independently at home: reforms in home care in 9 European countries.* Copenhagen: SFI – Danish National Centre for Social Research.

Timonen, V. et al (2012), Expanded, but not regulated: ambiguity in home care policy in Ireland. *Health and Social Care in the Community*, 20 (3): 310-318.

Triantafillou, J. et al (2010) *Informal Care in the Long-Term Care System: European overview paper*. Athens/Vienna: Interlinks.

Twigg, J. (2000) The medical-social boundary and the location of personal care. In. Warnes, A. et al (eds.) *Care Services for Later Life: Transformations and critiques*. London: Jessica Kingsley.

Ventura, A. D. et al (2013) Home-based palliative care: a systematic literature review of the self-reported unmet needs of patients and carers, *Palliative Medicine*, 28: 1146-1155.

Walsh, K. & O'Shea, E. (2009) *The Role of Migrant Care Workers in Ageing Societies: Context and experience in Ireland.* Galway: Irish Centre for Social Gerontology, National University of Ireland Galway.

Walsh, K. & Shutes, I. (2013) Care relationships, quality of care and migrant workers caring for older people. *Ageing and Society,* 33: 393-420.

Ward-Griffin, C. (2001). Negotiating care of frail elders: relationships between community nurses and family caregivers. *Canadian Journal of Nursing Research,* 33 (2): 63-81.

Ward-Griffin, C. (2002) Boundaries and connections between formal and informal caregivers. *Canadian Journal on Aging*, 21 (2): 205-216.

Ward-Griffin, C. et al. (2003). Relationships between families and nurses in long-term-care facilities: A critical analysis. *Canadian Journal of Nursing Research*, 35 (4): 150-174.

Ward-Griffin, C. & Marshall, V. W. (2003) Reconceptualizing the relationship between 'public' and 'private' eldercare. *Journal of Aging Studies,* 17 (2): 189-208.

Ward-Griffin, C. & McKeever, P. (2000). Relationships between nurses and family caregivers: partners in care? *Advances in Nursing Science*, 22 (3): 89-103.

Watkinson-Powell, A. et al (2014) Food provision for older people receiving home care from the perspectives of home care workers. *Health and Social Care in the Community*, 22 (5): 553-560.

Wibberley, G. (2013) The problem of a 'dirty workplace' in domiciliary care. *Health and Place*, 21: 156-162.

Wiles, J. (2003) Informal caregivers' experiences of formal support in a changing context. *Health and Social Care in the Community*, 11 (3): 189-207.

Williams, A. (2002) Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science and Medicine*, 55 (1): 141-154.

Working Group on Long Term Care (2008), *Long Term Care Report*, Dublin: Stationary Office.

Wren, M. et al (2012) *Towards the Development of a Predictive Model of Long-Term Care Demand for Northern Ireland and the Republic of Ireland*. Dublin: Centre for Health Policy and Management, Trinity College Dublin.

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