# Introduction

Multimorbidity, defined as the presence of two or more chronic diseases in an individual (LeReste et al., 2013; Smith & Dowd, 2007), is common in people over 75 years of age (Balanda, Barron, Fahy & McLoughlin, 2010; Savva & McDaid, 2011) and experienced by as many as 82% of people aged at least 85 years (Banerjee, 2015; WHO, 2011). Common tasks required for effective health and wellbeing self-management by the person with multimorbidity (PwM), with or without support, include symptom monitoring, diet management and exercise. Furthermore, the effort of self-management includes learning about conditions, managing medication and appointments as well as coordinating one’s lifestyle to accommodate the competing and challenging demands of each aspect of managing self-care and treatment (Eton et al., 2012; Sav et al., 2013).

The workload of managing health conditions, and its impact on personal functioning and wellbeing, is defined as ‘treatment burden’ by Eton et al. (2012) and is outlined in their conceptual Framework of Burden of Treatment in Primary Care. Key framework themes include: (1) the work required for self-care management; (2) factors that exacerbate the burden of treatment and self-management; and (3) problem-focused strategies developed by individuals and their caregivers to facilitate self-management.

Each theme is comprised of further sub-themes. First, the work of self-management for PwMs includes learning about conditions and treatment, conducting self-management activities, maintaining vigilance in self-management and maintaining appointments (Eton et al., 2012). Secondly, factors, that exacerbate self-management burden for PwMs, are divided into sub-themes including: challenges with medications, emotional difficulties with others, limitations of roles and activities, financial challenges, confusion about medical information, and health system challenges. Thirdly, for those with multimorbitiy, struggling to manage their own health and wellbeing, it is often necessary to establish creative strategies to address context-specific problems encountered in that care-management journey.

Such challenges lead to what Haggerty (2012) refers to as ‘a chaotic experience of care’, often warranting the assistance of family members or friends, referred to as informal carers (IC), who are most frequently the primary form of (unpaid) support of the older PwM. The need for help with and respite from the challenging work of health and wellness self-management is one reason why PwMs and ICs seek paid healthcare assistants (HCAs). Paid caregivers have a critical role to play in supporting older PwMs who wish to remain autonomous and independent, yet there has been little examination to date of the challenges borne by this crucial cohort of homecare workers in supporting older people to self-manage multiple health conditions at home.

A significant amount of research has been conducted in relation to caregiver burden, however, this literature largely examines the experiences of ICs (Mason et al., 2014; May et al., 2016; Sautter et al., 2014). To date, research into the experiences of home care workers has been largely driven by recruitment and retention concerns, with little examination of the care burden experienced by paid HCAs. While working as a HCA may be rewarding, aspects of the role also present significant challenges, which can negatively impact on staff retention and mental health among this workforce. It is mostly women who take up HCA roles (Butler, Wardamasky & Brennan-Ing, 2012) and their work often gets little recognition (Baines, Charlesworth & Daly, 2016). Staff turnover is significant within this sector and job satisfaction is, unsurprisingly, a factor impacting the retention of HCAs (Faul et al., 2010).

Stress process literature (Lyons, Cauley & Fredman, 2016; Peralin et al., 1990) examines the influence of social, economic and cultural factors outside the control of the caregiver within their roles. Particular aspects of the HCA’s role which most often impact their experience of working include the nature of the caring relationship as well as the extent of memory impairment of clients (Ben-Aire & lecovich, 2014). Furthermore, the nature of agency-based care work, often including poor compensation as well as limited autonomy and control over their work, has been linked to poor job satisfaction and greater work-related stress for care workers (Butler, Brennan-Ing, Wardamasky & Ashley, 2014; Zoeckler, 2017). Meanwhile, dealing with clients with challenging behaviours or who take advantage of workers, occupational safety concerns, excessive workload, time constraints and task repetition present challenges to the mental health of home care workers (Delp, Wallace, Geiger-Brown & Muntaner, 2010; Denton, Zeytinoglu & Davies, 2002).

This study is part of a larger project to develop and evaluate a digital, integrated care ecosystem to support older adults with multimorbidity to self-manage their health with support from their care network. Participants (n=67) included PwMs and members of the care networks, such as healthcare professionals (HCPs), ICs and HCAs. The focus of this article is on HCAs (n=17), a subset of the main study participants, and the issues they highlighted which align with Eton et al.’s (2012) concept of ‘treatment burden’ for PwMs. The findings presented here address a gap in the current literature by examining the care burden of HCAs, who are tasked with helping older PwMs to self-manage their own care.

# Methods

Focus groups were conducted with HCAs (n=17) from an organisation providing HCA services to clients in their own homes. Participants completed a 16-question survey gathering data on their work context, such as hours providing care and general characteristics of their client cohort. Survey data were transferred to Excel for descriptive quantitative analysis. Focus groups lasted between 45 and 120 minutes and questions were asked as a series of open-ended probes. Discussions were recorded and transcribed verbatim. Coding followed a thematic analysis approach using Nvivo (version 11) software. Initial codes were reviewed, duplicate themes consolidated and primary and secondary themes identified. Ethical approval was received from the research ethics committees of two relevant academic institutions.

# Results

HCA participants (mean age = 50 years) were mostly women (n=15) working part-time (average of 21 hours per week) who had been providing care for clients over 55 years of age with multimorbid conditions (diabetes, heart failure, heart disease and/or COPD) and/or additional comorbidities and/or cognitive impairment, for at least 6 months. This range of experience underpins the findings discussed in the paper. All participants had earned at least a second level education or equivalent. Main care duties included providing help with housework/meal preparation, managing and prompting medication, personal activities such as dressing, eating and bathing, and physical activities such as getting in and out of bed and assisting with physiotherapy exercises. HCAs work under the supervision of a care manager who is the official organisational liaison with the PwM and/or their ICs.

## The Work of Providing Care

#### Knowledge and Information

HCAs described supporting the PwM in managing their conditions by assisting with a wide range of tasks. Insufficient training and knowledge, for example about how to use medical devices such as oxygen machines, was identified by HCAs as a barrier to providing effective care: **‘**most of us who start as carers, we have very little training. We get our training when we start working’ (IE-05-0002). Two HCAs described clients who were required to use oxygen at home, but the HCAs were not provided with information and instructions about how to use the oxygen equipment. In one case this had been a source of great distress, as the client had subsequently died, and the HCA described feeling significant anxiety, guilt and worry, that incorrect use of the oxygen equipment had played a role.

Other HCAs described similar lack of knowledge about correct use of stair-lifts, hospital beds etc. Practical learning 'on the job' was valued and seen as crucial but often depended on how committed the HCA was to their job and to learning more. Clients and their ICs often assume that the HCA knows how to use medical equipment supplied for the PwM: 'they think you are the expert' (IE-05-0005); 'Sometimes they think we are like doctors or nurses, and we're not, we're only carers' (IE-05-0004). It was reported that some training was offered by homecare organisations, but none of the participants had received specific training in providing care for older adults with specific chronic illnesses or multimorbidity. Participants suggested that better communication between HCAs and the client's ICs might improve their ability to support the PwM: ‘when you are introduced to the client, to go into another room with the family and work out 'well she's on this, she has that' (IE-05-0004).

To guide the activities of the HCA, a home care plan is established for each client, based on input from a healthcare professional (HCP) involved with the client and, where relevant, family members. This plan, defined with a care manager from the homecare organisation, may include information on such issues as mobility or continence challenges, but the HCAs who participated in this study considered these care plans to be minimally informative: 'The care plan is just a few lines on a sheet. It doesn't mean anything to them [client].' (IE-05-0010); 'you get the care plan which basically lists out if they are mobile or immobile, if they are on meds and whatever’ (IE-05-0002); ‘it's very brief’ (IE-05-0006). *Lack* of information about *their* clients was identified as a key challenge for HCAs: 'you go into any house blind...because you don't know what is behind that door...you have no idea what you are going in to' (IE-05-0011); *‘*You don't get all of the information, or you get information that some people think is relevant enough but don't give you the overall picture.' (IE-05-0011).

#### Poor Communication

Lack of knowledge and information was seen as being exacerbated by poor communication between different HCAs, and between HCAs and other members of the PwM’s care network (e.g. HCPs and ICs). Having information on the PwMs conditions, test results, medication and patient care requirements was considered by HCAs as crucial for their work, but this was not always shared with them. Notification of care provision changes was expected: ‘if the client came out of hospital and there’s a change, you’d obviously be told that’ (IE-05-0006), but this is often not forthcoming or inconsistent: ‘you're not being told what went wrong in the hospital, what was diagnosed' (IE-05-0008).

Where multiple HCAs visit the same client, poor communication between carers was considered to contribute to the lack of information perceived as necessary for effective care provision: 'if you are coming and going, you don't always have the full picture' (IE-05-0011). HCA client visits do not typically overlap, therefore, HCAs do not always have the opportunity to relay information to each other in person. A paper journal, often maintained in the PwM’s home, for recording care provision notes, was not considered effective: 'sometimes you mightn't be able to understand the person's writing’ (IE-05-0006); ‘Or the notes … mightn't be in the place where it should be in the book’ (IE-05-0005). Access to the journal by the PwM and family members was also a concern: ‘…so you have to be careful what you are putting there’ (IE-05-0015). For these reasons, HCAs communicate mainly by phone (call or text) or email,: 'actually the communication is very bad between the carers, unless you know the other carer, maybe you have a phone number and you can send her a text or whatever' (IE-05-0005), but this depends on knowing the other HCA personally.

## Factors Exacerbating Treatment Burden

#### Medication and Symptoms

HCAs saw themselves as important actors in supporting medication management and adherence by PwMs. While not permitted to administer medication, HCAs described how they prompt clients in detail: ‘I will tell her to take it and put it in the [her] mouth, because we cannot do that’ (IE-05-0015). HCAs are also often relied upon to remind clients to take their medication at the relevant times: ‘… we've to go in and prompt medicines in the morning - and there could be 7 or 8, 9, 10 tablets [pills] that they've to take - I've a lady and she just can't take tablets in the morning. But I'm the only one there, … until the afternoon. So, when I come back I have to make sure' (IE-05-0005). Where formal care provision is limited, HCAs expressed concerns about potential gaps in the medication support for the PwM: 'he's forgetting to take them [medications], because he stopped the night carer coming in, and he's not taking his night meds and he's been saying to me, can you ring me in the evening and tell me?' (IE-05-0004).

In Ireland, ‘blister packs’[[1]](#endnote-1) are often used to support medication adherence where individuals have been prescribed multiple medications, often to be taken at different times during a day. HCAs highlighted that when medications are in a blister pack, it is often not possible to identify which specific tablet is which, or what they are being taken for, to fully understand the medication treatment plan. This exacerbates a perceived lack of information as outlined above. Dexterity challenges can pose an obstacle to opening blister packs, where medication must be manually pushed through a foil or paper backing. In addition to observing their clients struggle to open blister packs, HCAs also reported experiencing difficulties, such as tablets spilling and becoming stuck in the pack or lost due to problems with opening the packs: '...because you might be taking Monday’s out and Tuesday’s will fall out everywhere' (IE-05-0011); 'and then some blister packs, when you open them, and you take the tablets out, some of the little tablets don't come out' (IE-05-0007).

#### Emotional Challenges

Some HCAs reported that verbal abuse directed towards them by PwMs presents a considerable source of ongoing stress in their work: ‘believe me, talking of anger, it’s hellfire!’ (IE-05-0016); ‘the way he told me, the anger he has, for the first time in my life I feel like crying… this anger is too much’ (IE-05-0015). One HCA reported, ‘…words come out of his mouth like ‘bully’… ‘monkey’…spat on me…maybe you want to wash and dress him, it’s tough’ (IE-05-0017). HCAs gave allowance for how they viewed such behaviour, recognising that stress experienced by PwMs might relate to the health conditions of the PwM, particularly where dementia is present (offering a possible explanation for such behaviour): ‘they start to be aggressive because now they are getting frustrated that, I used to do this and look at me I can’t do anything now’ (IE-05-0015). Nonetheless, it was acknowledged that HCAs need to be prepared to manage aggressive behaviour as a routine part of their job: ‘caregivers must have a strategy to make sure they have the ability to handle that’ (IE-05-0016).

Notwithstanding the difficulties noted above, HCAs recounted that they frequently built close relationships with their clients and often saw themselves as a primary source of support for some PwMs: 'you do become, maybe the most important person... once the carer goes in, the family step way back and it's all yours' (IE-05-0002). HCAs expressed a sense of responsibility and duty to their clients: ‘if I left that and just ignored the symptoms, she would go from week to week, she would deteriorate’ (IE-05-0002). Worry about the safety of clients and their informal carers was identified by participants as sometimes placing a burden on the role of the HCA. A recurring example was where an older spouse or family member, in receipt of a carer allowance payment, may be considered the second official carer available in the home of a PwM who requires the support of two carers, for example to assist with mobility: ‘I find it hard to ask her and I feel sorry for her as well. She will be bending on this bed…she does not even have any training or manual handling. She could hurt herself’ (IE-05-0015).

Strain and worry was evident among HCAs who found it difficult to cope with clients’ health decline over time: ‘I find it upsetting’ (IE-05-0002). HCAs worried about clients outside work: 'sometimes I don't even want to go home, because I don't want to leave him, so it's affecting me at home that way’ (IE-05-0004). HCAs described stress related to the death of their clients, and the psychological impact of these experiences was evident, not only in terms of grief, but also of guilt around whether they could have done more for the client.

#### Systemic Obstacles

Lack of information about how to navigate the healthcare system can be challenging for people with chronic illnesses. HCAs described witnessing families struggling to secure care and support, because they do not have clear information about who to contact and how to go about putting supports in place: ‘you don't know whether you are getting the right care for the person...that's what I am saying about, about the system the way it is now. It's so disjointed, and people are running blind - families, carers, you name it, everyone.' (IE-05-0002). HCAs sometimes struggled to provide the best possible care to PwMs, in the absence of information about support services.

Lack of appropriate resources, such as hospital beds or other equipment, was identified as another recurring challenge encountered in providing home care. For example, one HCA described an older client who, after six months, still did not have a stand to hold his night-time catheter bag. She described it as stressful and worrying that she would regularly find the catheter bag left on the floor, posing a significant infection risk. She reported one occasion when the bag had been placed in the bed, where it had emptied during the night, leaving the man lying in urine until she came to care for him in the morning. Participants pointed out how the absence of necessary equipment and resources made it difficult to implement the training they had received and expressed frustration with understanding best practice but often being limited in their ability to implement it, in the home care context.

HCAs felt under significant pressure to provide adequate care in their allocated time: ‘it’s a strip bath, you have to strip him, you bath him, everything, you make his bed …that is a priority, you must do it in the morning, so then you have to make his meal, all those … they put [allocate] 30 minutes!’ (IE-05-0016). Sometimes the time allocated was considered sufficient but in many cases, HCAs felt additional time would be required to provide more holistic care: 'sometimes I'm just rushing in and out the door, I'm actually rushing to even write in the journal, you know, now I'd have an hour but I'd love to maybe bring her out for a walk as well, but I wouldn't be able to do that and her personal care as well' (IE-05-0001).

The extent of unrecognised depression among some PwMs was a concern noted by almost all HCAs: ‘But a lot of people don't realise that people in their eighties and nineties, you would think how could they be depressed?, but there is huge depression’ (IE-05-0010); ‘I have a woman that’s going blind, and she's very depressed at the moment…I find sometimes I go to her and she's sitting there crying’ (IE-05-0001); ‘it’s the worst thing’ (IE-05-0005); ‘That's why I think they need more time with their carers’ (IE-05-0001).

#### Role Limitations

Despite limited resources to support HCAs, it is clear that HCAs play a key role as front line support actors for PwMs. HCAs reported having the best knowledge of their clients and what care support they needed, but they were frustrated by how the limitations of their HCA role impacts their provision of holistic care. The responsibility HCAs have for tasks, such as making appointments or communicating with HCPs, varies depending on the involvement of others in the care network and the length of time the HCA has been working with the PwM: ‘after 4 years, they [the family] kind of leave it up to me’ (IE-05-0002). Most of the time, however, HCAs noted that while they gained considerable knowledge about their clients' wellbeing from observing them so regularly, they had no power to act on this: 'you are the man in the middle but you're not really' (IE-05-0011); ‘you kind of have to be aware of your place’ (IE-05-0006); ‘you have no power like, you are just there, to supervise what’s happening, observe and give the information but you are not acting, you can't act’ (IE-05-0008).

Monitoring symptoms is often part of managing chronic illness. HCAs noted that monitoring symptoms was outside their role. Despite this, HCAs often support the management and monitoring of symptoms by prompting clients to take readings such as weight or blood pressure, or assisting with the recording of readings taken by clients. This was most often in response to observing PwMs struggling with these self-management tasks. One HCA reported monitoring the blood glucose readings taken by her client, because she had noticed that these were not being recorded correctly - the PwM, forgetting what the reading had been, was recording an estimated value. Furthermore, HCAs reported watching for symptoms or signs of an illness exacerbation or infection: ‘…if you are toileting them and washing them and that, you can determine whether there is maybe a urinary tract infection, and you'd know maybe by their manner…' (IE-05-0002).

## Problem-Focused Strategies

#### Knowledge and Information

HCAs described building up a relationship and piecing together information about the PwM, as they grew to more fully understand the care needs: ‘… the care plan will be: companionship, helping personal hygiene and things, but you build it by yourself when you go there… how he gets up, you help him like that, to go to the bathroom - you learn it from stage to stage, you know' (IE-05-0008). Participants depended on the information they gathered through their practice, to inform them about the care needs of their clients: ‘I find … that if I go in and look after a client, I usually draw up a little synopsis' (IE-05-0011).

#### Supporting Medication Adherence

HCAs showed a sense of responsibility to ensure the wellbeing of their clients and sought ways to ensure medication adherence, a key health and wellbeing strategy for PwMs (Sinnott & Bradley, 2015; Summer Meranius & Engstrom, 2015). While their role does not permit direct administration of medications, HCAs regularly face the dilemma of having to decide whether to leave their client without medication or find creative ways to help the PwM take medication when it is due to be taken. To this end, HCAs employed various strategies, such as leaving notes or putting the pills to be taken in a prominent location: ‘I say - that's the evening tablets, need to be taken at 9 o'clock. And that note is there, next to her bed. But I come in in the morning and it's gone, she's taken them. But if I have not left the note there, I cannot rely that she would take it by herself' (IE-05-0008). One HCA described putting medications into a container to ensure that her client took all of her tablets: ‘what we do is we put the morning ones in a pot. And she knows that, well, ‘that pot has to be empty after my breakfast' and then the evening ones go in a pot by her bedside, and she knows ‘before I get into bed or as I'm getting into bed that pot has to be emptied' (IE-05-0007).

HCAs also frequently set reminders to ensure prescriptions were collected on time from the pharmacy: 'I had to leave a note in the journal for the other carer, just to say on the 7th of every month, can you make sure that, whatever carer it is, that we ring the pharmacy to have the blister pack ready for the next morning…because the lady had to go the whole day because the pharmacy hadn't got the blister pack ready’ (IE-05-0004). Information considered important to communicate to the next carer, was often passed on by leaving notes in prominent locations in the home, such as cupboards.

# Discussion

#### Summary of main findings

Treatment burden has been recognised in both individuals with chronic illnesses (Eton et al., 2012) and their family caregivers. Scant attention has been given to the care burden experienced by paid caregivers. HCAs often find themselves looking after older people with multimorbid, chronic health conditions, a responsibility few take lightly.

Policy objectives in Ireland include increasing opportunities and capacity for people to ‘live in their homes for as long as possible’ (Department of Health [DoH], 2012, p.6), while self-managing their health conditions within the community setting. Availability of paid care support, however, remains problematic for many, with a reduction from eight hours in 2000 to a little over four material home-care hours per client per week in 2016 (Care Alliance Ireland, 2016). It is unsurprising, therefore, that HCAs consistently expressed frustration about time constraints imposed on their care provision.

As noted in the care-worker retention literature, a range of obstacles exist, which HCAs find difficult to overcome in their work caring for older PwMs. Inadequate information and training, lack of sufficient time to complete tasks, and unreasonable expectations of clients or family members were all identified as barriers to providing the best care. Difficulties in providing medication support, and poor communication were highlighted as further impacting care provision. Additionally, work-related stress including emotional stress, role limitations, inadequate training and systemic obstacles were identified as ongoing challenges faced by HCAs providing care for older PwMs.

#### Study strengths and limitations

The main study strength lies in its focus on the care burden experienced by HCAs working to support older clients with multimorbidity to self-manage complex and burdensome self-care management routines and maximise their quality of life. The small sample size is a clear limitation in this study, as is the inclusion of care workers from a single homecare organisation and the absence of national demographic data for comparison. Nonetheless, the issues raised highlight the need for further examination of the care burden experienced by this essential cohort of home healthcare workers and the importance of identifying possible strategies to address such burden.

#### Relation to existing literature

The findings outlined in this paper, while not examining why HCAs leave their jobs, concur with the existing literature about some of the key challenges facing HCAs in their work with older PwMs. The combination of stress factors reported by HCAs in this study suggest that the concept of care burden applies to HCAs working with older PwMs in much the same way as Haggerty (2012) and others (Eton et al., 2012) have applied the concept of treatment burden to PwMs. These experiences echo those found by Rubery et al. (2015) in their examination of the stress impact on care workers of ‘fragmented time’ and the threat such organisational time management strategies pose to recruitment and retention in this sector.

Themes emerging from the data align particularly closely with the conceptual Framework of Burden of Treatment in Primary Care by Eton et al. (2012), which has been used above to order the findings into key themes for discussion. In line with Eton et al.’s (2012) framework, learning about conditions and treatment was a theme which HCAs identified as a challenging part of their work in supporting PwMs. Necessary knowledge is essential for HCAs to understand how to support clients, as is having relevant information and receiving such information in a timely manner. Findings show, however, that care provision changes are not always communicated quickly or completely enough, if at all. Limited channels to facilitate communication between HCAs, were also identified as problematic. Furthermore, in line with Eton et al’s. second theme, HCAs identified a range of factors that exacerbate the care burden of supporting older PwMs to self-manage their own care. Challenges included providing medication support, emotional difficulties with others, role limitations and systemic obstacles.

Finally, like PwMs, HCAs also reported having to develop a range of strategies to address specific issues arising when assisting PwMs, such as supporting medication adherence and acquiring or providing information. Phone access to supervisors and care coordinators is part of the accepted care supervision arrangement for HCAs. In practical terms, however, the HCA in a homecare setting is most often expected to use their initiative and training to manage general issues as they arise during their home visits. Such problem-focussed strategy development mirrors the third key theme of the Eton et al. framework (2012) for PwMs experiencing treatment burden.

This paper contributes a timely perspective on an emerging concern within community healthcare provision by addressing a gap in the current literature by examining care network support of self-management of multimorbidity for PwMs and the care burden experienced by HCAs providing this support. Furthermore, it highlights how little progress has been made in examining how PwMs and their home care providers might be supported in managing an increasing number of comorbid chronic health conditions and the in-home self-management burden often present with multimorbidity. Most importantly, the challenges, experienced by HCAs, align with those identified by Eton et al. (2012) as experienced by PwMs and contributing to treatment burden. The concept of *care burden* is found to be part of the lived experiences of HCAs supporting older PwMs to self-manage their own care.

#### Implications for practice and future research

To secure a workforce for which there will be an increasing demand, it is necessary to further explore how to mitigate the impact of care burden for HCAs. This, in part, requires greater availability of further education, training and upskilling of HCAs to ensure the provision of quality care for PwMs is in line with best practice (Jansen et al., 2017). Research examining the social, economic and cultural factors impacting HCA stress will also have an important contribution to make in considering the care provision experience of HCAs in the expanding normative context of direct, in-home, paid care provision. Most importantly, it is necessary to develop strategies to retain and support this essential cohort of caregivers in meeting the physical and emotional demands of providing care with compassion, dignity and respect for older PwMs.

## Declaration of Conflicting Interests

The authors declared no potential conflict of interests in relation to the research, authorship or publication of this article.

## References

Baines, D., Charlesworth, S. & Daly, T. (2016). Underpaid, unpaid, unseen, unheard and unhappy? Care work in the context of constraint, *Journal of Industrial Relations*. 58(4): 449-454. doi/10.1177/0022185616655981

Balanda, K., Barron, S., Fahy, L., & McLaughlin, A. (2010). *Making chronic conditions count: Hypertension, stroke, coronary heart disease, diabetes.* Institute of Public Health in Ireland.

Banerjee, S. (2015) Multimorbidity: older adults need health care that can count past one, *The Lancet*, Vol. 385: 587-589.

Ben-Arie, A., & lecovich, E. (2014). Factors explaining the job satisfaction of home care workers who left their older care recipients in Israel. *Home Health Care Services Quarterly*, *33*(4), 211–228. https://doi.org/10.1080/01621424.2014.956958

Butler, S. S., Wardamasky, S., & Brennan-Ing, M. (2012). Older women caring for older women: the rewards and challenges of the home care aide job. *Journal of Women & Aging*, *24*(3), 194–215. https://doi.org/10.1080/08952841.2012.639667

Butler, S., Brennan-Ing, M., Wardamasky, S., & Ashley, A. (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. https://doi.org/10.1177/0733464813495958

Care Alliance Ireland (2016). Briefing paper 1: Analysis of home care supports funded by the HSE 2008-2016. Dublin, Ireland: Author.

Delp, L., Wallace, S., Geiger-Brown, J. & Muntaner, C. (2010). Job stress and job satisfaction: Home care workers in a consumer‐directed model of care, *Health Services Research,* 45(4), 922-940. [**https://doi.org/10.1111/j.1475-6773.2010.01112.x**](https://doi.org/10.1111/j.1475-6773.2010.01112.x)

Department of Health (2012). Future health: A strategic framework for reform of the health service 2012–2015. http://health.gov.ie/blog/publications/future-health-a-strategic-framework-for-reform-of-the-health-service-2012-2015/

Denton, M. A., Zeytinoglu, I. U., & Davies, S. (2002). Working in clients’ homes: the impact on the mental health and well-being of visiting home care workers. *Home Health Care Services Quarterly*, *21*(1), 1–27. https://doi.org/10.1300/J027v21n01\_01 [doi]

Eton, D. T., Ramalho de Oliveira, D., Egginton, J. S., Ridgeway, J. L., Odell, L., May, C. R., & Montori, V. M. (2012). Building a measurement framework of burden of treatment in complex patients with chronic conditions: a qualitative study. *Patient Relat Outcome Meas*, *3*, 39–49. https://doi.org/10.2147/prom.s34681

Faul, A. C., Schapmire, T. J., D’Ambrosio, J., Feaster, D., Oak, C. S., & Farley, A. (2010). Promoting sustainability in frontline home care aides: Understanding factors affecting job retention in the home care workforce. *Home Health Care Management & Practice*, *22*, 408–416. https://doi.org/10.1177/1084822309348896

Haggerty, J. (2012). Ordering the chaos for patients with multimorbidity, *BMJ*, 2012:345.

Jansen, B., Brazil, K., Passmore, H. Buchanan, H., Maxwell, D., MacIlfatrick, S…, Parsons, C. (2017). Exploring healthcare assistants’ role and experience in pain assessment and management for people with advanced dementia towards the end of life: a qualitative study, *BMC Palliative Care*, *16*(6).

Le Reste J.Y., Nabbe, P., Manceau, B., Lygidakis, C., Doerr, C., Linfner, H…., Lietard, C. (2013) The European General Practice Research Network presents a comprehensive definition of multimorbidity in family medicine and long term care, following a systematic review of relevant literature. [*Journal of the American Medical Directors Association*](http://www.sciencedirect.com/science/journal/15258610)**2013, 14(5)**, 319–325

Lyons, J., Cauley, J. & Fredman, L. (2015) The Effect of Transitions in Caregiving Status and Intensity on Perceived Stress Among 992 Female Caregivers and Noncaregivers, The Journals of Gerontology: Series A, Volume 70, Issue 8.

Mason B., Nanton V., Epiphaniou E., Murray, S., Donaldson, A., Shipman, C…., Boyd, K. (2016) ‘My body's falling apart.’ Understanding the experiences of patients with advanced multimorbidity to improve care: serial interviews with patients and carers. *BMJ Supportive & Palliative Care,***6:**60-65.

May, C., Cummings, A., Myall, A., Harvey, J., Pope, C., Griffiths, P…., Richardson, A., (2016) Experiences of long-term life-limiting conditions among patients and carers: what can we learn from a meta-review of systematic reviews of qualitative studies of chronic heart failure, chronic obstructive pulmonary disease and chronic kidney disease? *BMJ Open* 6:e011694. doi: 10.1136/bmjopen-2016-011694

Peralin, L., Mullan, J., Semple, S. & Skaff, M. (1990) Caregiving and the Stress Process: An Overview of Concepts and Their Measures, The Gerontologist, Volume 30, Issue 5: Pages 583–594. <https://doi.org/10.1093/geront/30.5.583>

Rubery, J., Grimshaw, D., Hebson, G. & Ugarte, S. (2015) “It's all about time”: Time as contested terrain in the management and experience of domiciliary care work in England, [*Special Issue: Human Resource Management in Health Care and Elderly Care*](https://onlinelibrary.wiley.com/toc/1099050x/2015/54/5) 54(5): 753-772. [**https://doi.org/10.1002/hrm.21685**](https://doi.org/10.1002/hrm.21685)

Sautter, J., Tulsky, J., Johnson, K., Olsen, M., Burton-Chase, A., Hoff Lindquist, J…., Steinhauser, K. (2014) Caregiver experience during advanced chronic illness and last year of life. *Journal of the American Geriatrics Society*, 62(6):1082-1090. <https://doi.org/10.1111/jgs.12841>

Sav A., Kendall E., McMillan S., Kelly F., Whitty J., King M. & Wheeler A. (2013) 'You say treatment, I say hard work': treatment burden among people with chronic illness and their carers in Australia, *Health & Social Care in the Community* 2013 vol: 21 (6) pp: 665-74

Savva, G. & McDaid, O. (2011) *Multimorbidity in the older population (Briefing paper).* Centre for Ageing Research and Development in Ireland (CARDI). Retrieved from <https://www.lenus.ie/handle/10147/202430>

Sinnott, C. and Bradley, C. (2015) Multimorbidity or polypharmacy: two sides of the same coin? *Journal of Comorbidity. 5*(1):29-31.

Smith, S. and Dowd, T. (2007) Chronic diseases: what happens when they come in multiples? *British Journal of General Practice*, *57*(537): 268-270.

Summer Meranius, M. and Engstrom, G. (2015). Experiences of self-management of medications among older people with multimorbidity. *Journal of clinical nursing*, *24* (19-20).

World Health Organisation (WHO) (2011). *Noncommunicable diseases country profiles 2011*. Retrieved from <http://www.who.int/nmh/publications/ncd_profiles2011/en/>

Zoeckler, J. (2017). Occupational stress among home healthcare workers: Integrating worker and agency-level factors, *NEW SOLUTIONS: A Journal of Environmental and Occupational Health Policy*, Vol 27, Issue 4, pp. 524 – 542. [https://doi.org/10.1177/1048291117742678](https://doi.org/10.1177%2F1048291117742678)

**Table: HCA participant demographics**

|  |  |
| --- | --- |
| Gender | 2 = Male  15 = Female |
| Age (Mean age = 50) | 30-39 = 1  40-49 = 3  50-59 = 9  60+ = 3  Unanswered = 1 |
| Education | Completed second level = 5  Diploma/Certificate level = 11  Postgraduate = 1 |
| Care hours worked per week | Up to 19 hours = 5  20 – 29 hours = 6  30 + hours = 6 |
| Months worked as a HCA | Up to 12 months = 7  13 to 24 months = 6  More than 2 years = 3  Unanswered = 1 |
| Age range of care recipients | 55 to 100 years |
| Co-morbid Chronic conditions supported by HCA | COPD = 3  Diabetes = 10  Congestive Heart Failure = 3  Coronary Heart Disease = 4  Cognitive Impairment or Dementia = 14  Other chronic conditions = 4 |

1. Presentation of medication for a week or month, with the medication for each day or time of the day (morning, evening etc.) pre-packaged in separate ‘blisters’ to ensure correct medications are taken at prescribed times. [↑](#endnote-ref-1)